



CIVIC SURVEY ON THE RESPECT OF UNNECESSARY PAIN PATIENTS' RIGHTS IN EUROPE

**Report on the Patients' Right to avoid unnecessary suffering and pain
1° Edition, 2013**



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INTRODUCTION

In 2004 the World Health Organization declared that the right not to suffer is an inalienable human right, yet it is still little respected. While, fortunately, cancer pain is intended as pathology, with many associations committed towards its recognition, chronic pain considered as a disease is still little known by both health professionals and the public in general.

However, encouraging signs show that commitment against unnecessary pain will soon be one of the policies in the European Agenda regarding health issues. Quite a significant number of data have been collected by scientists, private companies and governments regarding the diffusion of chronic pain and its impact both on society and on the economy. New laws, such as the one passed in Italy, have proposed innovative contents to be put into practice.

At the same time the drive of patients' organizations towards a more active role in reducing pain and in promoting a new policy on pain relief is growing.

Despite all this activity, the condition of patients affected by chronic pain is still very serious, as patients' associations from different European countries can testify. What is stated in theory is often denied in practice. This condition requires the promotion of strong patient-oriented policies against pain.

This civic survey is a first attempt in which a widespread coalition of patients and citizen organizations represents the point of view of patients in the European policies on pain. The first deals primarily with chronic pain and the right not to suffer, the second, more generally, with health policies and the protection of patients.

This work is a contribution to reflection, hopefully useful to stir interest in those who hold institutional roles and are responsible for policy decisions and also the professionals, civil society organizations and the general public are invited to take the issue of pain seriously, especially chronic pain, which not only causes individual suffering but has an economic and social impact greater than it is thought.

The presentation of this work however needs two specific general notations. On the one hand, the survey in this report has achieved over the last few months an increasing involvement and appreciation to the point that it is planning a second edition later this year which will collect additional data. On the other, it is part of a more ambitious study as we will clearly show in the following chapters. In fact, starting from the patients' experiences, the goal is to identify both at national and at European level guidelines and recommendations against pain.

CHAPTER 1 – EUROPEAN DATA

1.1 Definition and conditions of chronic pain ¹

The International Association for the Study of Pain (IASP) has defined pain “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”.

Chronic pain can be defined as pain that lasts beyond the normal course of an acute disease or beyond the expected time of healing. It may in fact continue indefinitely.

The type of pain that is not relieved despite appropriate treatment is referred to as non-treatable pain.

Among the typical conditions of chronic pain we can mention:

- Osteoarthritis
- Rheumatoid Arthritis
- Lumbago and pain in the shoulder and neck
- Headache, including migraine
- Neoplastic pain
- Myofascial pain syndrome (Muscle pain)
- Post-thoracotomy pain
- Neuropathic pain
- Herpes zoster (shingles) and post-herpetic neuralgia
- Trigeminal Neuralgia
- Diabetic neuropathy
- Temporomandibular joint disorder
- Post-mastectomy pain
- Angina pectoris
- Phantom limb pain

1.2 Figures regarding chronic pain in Europe

Currently, comprehensive epidemiological investigations at pan-European level able to define the importance of the issue of pain are not yet available. However, a number of more limited surveys are not sufficient to prove beyond any doubt that today in Europe pain is a major health problem, and that chronic pain remains one of the less known and less addressed medical issues. Statistics show the incredibly negative impact of chronic pain and underline the extent of the problem, including the economic costs to society and identify the serious reduction in the quality of life of millions of people suffering from it.

- According to EFIC, the European Federation of IASP Chapters², chronic pain has currently reached extremely high rates throughout Europe;
- Latest figures suggest that one in five people across Europe have been suffering from chronic pain for more than three months and that one person in eleven deals with pain on a daily basis;
- In the 27 member states of the European Union 100 million people live with chronic pain and often with agonizing pain for a period of more than seven years - but a fifth lives with this torture for 20 years or more without getting the pain relief they need;

¹ Source: www.aisd.it/page.php?24.

² These data were presented in Brussels on 12 October 2012 by Professor Hans Georg Kress, EFIC President.

- Throughout Europe chronic pain accounts for almost 500 million lost working days every year, costing the economy an estimated 34 billion Euros;
- 19% of patients with moderate or severe chronic pain have lost their job. These patients are seven times more likely to give up their employment compared to the rest of the population;
- The survey "Epidemiology of chronic non-cancer pain in Europe" came to the conclusion that 22% of those suffering from chronic pain is absent from work for more than ten days;
- Proper management of chronic pain is often overlooked and many patients are treated inadequately, too little or not at all: only 2% of patients suffering from pain in Europe are followed by a specialist, one third of patients with chronic pain are not even taken care of.

Both the scientific community and the associations of patients are aware that the main cause of this lack of treatment is probably due to the fact that pain is still seen as a mere symptom of a disease. However, what is really needed is a new vision of chronic pain: to recognize chronic pain as a disease in its own right.

While awaiting this recognition, the costs associated with chronic pain and the right of sufferers to enjoy a reasonable quality of life require that this issue be recognized and addressed at a wider level.

1.3 Effects and non economic costs of chronic pain

The impact of chronic pain, however, should not be considered only in economic terms. Chronic pain is a complex and devastating problem which can actually ruin people's lives. In Europe, it has serious negative effects on the quality of life of people who suffer from it, as well as that of their families. In the absence of adequate treatment, those who suffer from chronic pain are often unable to work or even to perform the simplest tasks. As a result, patients are often subject to physical and psychosocial deprivation, including poor nutrition and weight loss, reduction in activity, dyssomnia, social isolation, marital distress, unemployment and financial problems, anxiety, fear and depression.

In addition to the huge strain that chronic pain puts on people's lives, there is evidence from all over Europe that the suffering experienced by patients is exacerbated by external forces: cultural stigma, inadequate treatments, ignorance amongst doctors and politicians³.

Data in percentage regarding each individual European country shows that Norway is the country with the highest incidence of pain: nearly 1 out of 3 Norwegians (30% of the population) suffer from chronic pain followed by Poland (27%) and Italy (26%). Spain shows a smaller number of sufferers (12%) with Ireland and Great Britain (13%) following close by. Moreover, according to statistics released in August 2012 during the 14th World Congress on Pain, 26% of adult Americans (about 100 million) suffer from chronic pain. Regardless of the country of origin, the typical patients are women (56%) of average age between 40 and 50. In 1 case out of 5 chronic pain leads to losing one's job or downsizing one's professional career. Furthermore, in 21% of cases it affects the person's emotional state, leading eventually to depression.

Experts identify also an inverse relationship between the level of education and the degree and persistence of pain. 30% of people with a medium to low level of education experience severe pain, while the percentage drops to 17-18% in the population with a high level of education. This phenomenon can be explained by a supposed better ability of more educated individuals to communicate with one's doctor⁴.

³ Source: www.epgonline.org/documents/mundipharma/Pain%20Manifesto%20PRINT%20%284%29.pdf

⁴ See "Pathos", Journal of Pain Research and Therapy Volume 19, number 3, 2012, www.pathosjournal.com/doc/Pathos_19_03_2012.pdf

1.4 The European Year Against Pain⁵

The 2012-2013 Global Year Against Visceral Pain campaign was launched on October 15, 2012. This year, the IASP⁶ initiative will focus global attention on pain that originates in or near the internal organs of the body⁷. At the same time, was launched by EFIC the first "European Year against Pain" (EYAP)⁸.

The yearly campaign is dedicated to increase public awareness of the challenges of chronic pain. This European Year against Pain will highlight the difficult problems related to visceral pain, uniting patient support groups, doctors and researchers to improve the recognition and treatment of these multiple conditions.

Visceral pain is the most frequent form of pain, felt by most people at one time or another, the number one reason for patients to seek medical attention, and yet it is insufficiently treated as it is considered just a symptom of an underlying disease: if we treat the disease the pain will go away - an approach that ignores that many forms of visceral pain are diseases in their own right and require focused and specific therapies.

Visceral pain – pain which comes from the inner organs – is second only to trauma as the reason why patients visit emergency rooms in hospitals. Women report it three times more often than men. The condition is often diffuse and poorly localizable; many chronic visceral pain sufferers are not adequately diagnosed and treated.

The rate of visceral pain is both impressive and alarming, as demonstrated by the following data:

- 20-30% of the population suffers from dyspepsia, but only in half of these patients an organic cause can be identified;
- it is estimated that irritable bowel syndrome (IBS) affects between 6% and 25% of the population, depending on the study and also on gender it numbers about half the requests for gastroenterologist consultations. In Germany, for example, IBS occurs in approximately 16% of women, but only in 8% of men;
- bladder pain affects women more frequently than men, that is 900 women out of 100,000 who suffer from it;
- one in two women suffer from menstrual pain; in 10% of cases the pain is so severe that it is the cause of sick leave from work each month;
- on a global scale, the number of women suffering from visceral pain shows an incidence three times higher than in men.

The European Year Against Pain focuses on the education of a specific area of pain for health professionals, institutions and the public, with information⁹ material on various aspects of visceral pain, including chronic pain to the chest, chronic pelvic pain and pain in the gallbladder.

⁵ Bibliography available on the site: www.pharmastar.it/index.html?cat=23&id=9334

⁶ IASP chapters, a multidisciplinary professional organisation in the field of pain research and medicine, who count a membership of close to 20,000 physicians, basic researchers, nurses, physiotherapists, psychologists and other healthcare professionals across Europe, who are involved in pain management and pain research.

⁷ www.iasp-pain.org/Content/NavigationMenu/GlobalYearAgainstPain/GlobalYearAgainstVisceralPain/default.htm

⁸ www.efic.org/index.asp?sub=F8AMLHLAP9216P&topicsid=256#view

⁹ In depth information on the types of abdominal pain can be viewed at www.efic.org

CHAPTER 2 - PAIN AND COMPASSIONATE CARE

2.1 The role of patients' organizations

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 a 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 phenomenon, 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 organising 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 in counteracting pain, whether acute, chronic or severe and, in general, unnecessary pain deriving from lack of specific treatment or when it is overlooked.

Unfortunately, there are many ways 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 for patients, rude words, 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 the 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).

2.2 The issue of Pain in the Charter of Rights

The objectives of the Charters of Rights regarding health care are the proclamation of a "set of rights" which are clarifications and specifications necessary to give substance to the more general right to health. Widely used in health care, the citizens' Charter of Rights is a tool to understand and interpret the more general constitutional rights towards health. The Charter shows also specific reference to the issue of pain. Below are listed just a few of these rights which represent particularly important premises relevant for the realization of the civic survey shown in this Report.

The first paper, not in order of time, covers a wide spectrum of rights according to a geographical point of view, since it was drafted and proclaimed in a European context, including precisely the right to avoid unnecessary suffering and pain.

The other two 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. As shown in the chapter regarding the methodology of the survey and the identification of the factors of analysis, these are the two starting points for the whole study; one was drawn up in Ireland and the other in Italy and were written, developed and promoted by patients' associations and citizens. Both Charters can be signed by all those civic organizations and subjects who are interested in the issue.

2.2.1 European Charter of Patients' Rights

The European Charter of Patients' Rights is 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 fundamental for European citizens and health services, even if they are at risk, among other things, due to the global financial crisis of the national welfare system:

1 Right to Preventive Measures

Every individual has the right to a proper service in order to prevent illnesses.

2 Right of Access

Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services.

3 Right to Information

Every individual has the right to access all information regarding his/her state of health, the health services and how to use them, and all the scientific research and technological innovation available.

4 Right to Consent

Every individual has the right of access to all information that might enable him/her to actively participate in the decisions regarding his/her health; this information is a prerequisite for any procedure and treatment, including the participation in scientific research.

5 Right to Free Choice

Each individual has the right to freely choose among different treatment procedures and providers on the basis of adequate information.

6 Right to Privacy and Confidentiality

Every individual has the right to the confidentiality of personal information, including that regarding his/her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his/her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatment in general.

7 Right to Respect of Patients' Time

Each individual has the right to receive necessary treatment within a swift and predetermined period of time. This right applies at each phase of the treatment.

8 Right to the Observance of Quality Standards

Each individual has the right of access to high quality health services on the basis of the specification and observance of precise standards.

9 Right to Safety

Each individual has the right to be free from harm caused by the poor functioning of health services, medical malpractice and errors, and the right of access to health services and treatments that meet high safety standards.

10 Right to Innovation

Each individual has the right of access to innovative procedures, including diagnostic procedures, according to international standards and independently of economic or financial considerations.

11 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.

12 Right to Personalized Treatment

Each individual has the right to diagnostic or therapeutic programmes tailored as much as possible to his/her personal needs.

13 Right to Complain

Each individual has the right to complain whenever he/she has suffered harmful treatment and the right to receive a response or other feedback.

14 Right to Compensation

Each individual has the right to receive sufficient compensation within a reasonably short time whenever he/she has suffered physical or moral and psychological harm caused by a health service treatment.

Rights of Active Citizenship:

In order to promote and verify the implementation of the above stated patients' rights, organized groups of citizens have both the right and the unique role of actively supporting and empowering individuals in the protection of their own rights. These active citizenship rights are contained in article 12, section 1, of the Charter of Fundamental Rights.

1. *Right to perform general interest activities*
2. *Right to perform advocacy activities*
3. *Right to participate in policy-making*

2.2.2 Ireland: Charter of Rights for people living with Chronic Pain¹⁰

Written by Chronic Pain Ireland, the following Charter was drawn up and approved by the Governing Body of Chronic Pain Ireland on 19 November, 2009.

1. We have the right to be believed.
2. We have the right to be treated with dignity and respect.
3. We have the right to have our pain treated and managed at the earliest possible stage.
4. We have the right of access to the best possible technologies and therapies in pain treatment and management.

¹⁰ www.chronicpain.ie

5. We have the right to be informed about all the pain management options available so that we can make best decisions and choices for our wellbeing.
6. We have the right to live with the least amount of pain possible.
7. We have the right to be treated on at least an equal footing with all others who have been diagnosed as having a chronic illness.
8. The Relief of Pain should be declared a fundamental human right as per the central theme adopted by IASP, EFIC and the WHO at a conference in Geneva on the 11th October 2004.
9. We should not be left to suffer in silence and ignorance.

2.2.3 Italy: Charter of Rights against unnecessary pain¹¹

The Charter of Rights against unnecessary pain was promoted by Cittadinanzattiva in 2005 with the aim to declare and protect a group of rights still too often violated.

It was drawn up soon after the information campaign "Let's abolish unnecessary pain" and has benefited from the collaboration of a number of people active in the field.

The Following Charter intends to inform citizens about pain and promote its prevention, control and treatment; the subscription to the Charter is entrusted to citizens' organisations involved in safeguarding health rights, as well as healthcare professionals and the institutional bodies exerting governing responsibilities at different levels.

1 Right not to suffer unnecessarily

Every individual has the right to have his/her pain alleviated as efficiently and rapidly as possible.

In the past, ignorance, prejudice and resignation have prevented to adequately address pain associated with disease. In fact, pain is a symptom that should be treated with the same care used in preventing the disease in order to avoid it becoming chronic and thus become a "disease" in itself.

It is therefore necessary to build a new cultural approach towards suffering and unnecessary pain and make pain therapy an integral part of the therapeutic process. Every individual has the right to know that pain must not be necessarily tolerated, but that much of the suffering can be relieved and cured by intervening with the right therapy. Pain must be eliminated, or at least mitigated where possible since it heavily affects the quality of life. It is a right which must be recognized and respected always and everywhere, from hospital wards to long term care facilities, from the emergency rooms to the patients' homes.

2 Right to the acknowledgement of pain

Every individual has the right to be listened to and believed when reporting personal pain.

Pain has a strong subjective component, since the individual who is suffering from it is affected by many factors, as clearly shown by the literature on this issue. To intervene in a more appropriate manner, operators have a duty to listen, believe and consider the suffering. Citizens must be free to report the pain, with their own way of describing it and feeling it, without fear of the doctor's judgment, which in turn has the duty to interpret in the best way what the patient is trying to communicate.

3 Right to access pain therapy

Every individual has the right to access the treatment needed to alleviate pain.

¹¹ <http://www.cittadinanzattiva.it/corporate/salute/1954-carta-dei-diritti-sul-dolore-inutile.html>

There are currently still many limitations regarding access to pain relief. The greatest obstacle is represented by a cultural bias, which persists in the medical profession, also due to the lack of specific training for both university students and professionals. In addition to these resistances there are also excessively rigid procedures, such as the failure to consider certain types of pain, concerns of an economic-financial nature and the widespread inadequacy of health facilities. To make the treatment of pain accessible what are essential are the recognition and the sharing of a series of key requirements:

- consideration and care for the pain experienced by the patient should be a quality standard in the professional and an ethical duty of the entire team of operators, regardless of ethical, religious or philosophical beliefs, in order to ensure the assisted the best possible quality of life;
- all types of pain deserve equal consideration, no matter what the pathology or event that may have caused it. Therefore, even people nearing the end of their life have the equal right to be cared for and also those who suffer from chronic non-cancer pain and acute pain (childbirth, trauma from surgery or those who needs to be treated at A&E) and, in particular, all women should be allowed to decide (according to their clinical situation) to give birth without pain;
- public health services must be able to provide adequate assistance to pain both inside and outside health facilities. The latter should provide a service in pain therapy (simple or complex, depending on the quality and quantity of services provided) qualitatively compliant with the latest international guidelines and able to ensure appropriate treatment to all those in need. Access to treatment on the territory must be guaranteed especially through home services referring to the WHO guidelines, ensuring an easier availability of prescription and administration of medication and avoiding the suspension of continuity of care;
- drugs and techniques for the treatment of pain, and all the technical stages for their correct administration, must be among the public health system services offered to all citizens. Every individual has a right to access innovative procedures according to international standards, without economic or financial impediments.

4 Right to qualified assistance

Every individual has the right to receive pain assistance in observance of the latest approved quality standards.

Everyone has the right to receive assistance to relieve pain by properly trained and updated professionals, so as to guarantee the respect of the international quality standards.

It is necessary that the knowledge of the issue of "pain" (now considered the fifth vital sign), its quantification (measurement of pain) and treatment options become professional skills among all health operators, in order to guarantee citizens alleviation of their suffering, even in the absence of specialists. It is important that the measurement of pain be carried out through validated methods at international level and that its registration be indicated in the medical record. It is unacceptable that, even when laws provide tools to facilitate the prescription of opiate drugs, patients are denied the preparation or that doctors and practitioners are unprepared or unavailable.

5 Right to continued assistance

Every person has the right to have his/her pain relieved continuously and assiduously throughout all phases of illness.

Pain should be regularly monitored in all phases of the disease; continuity of care could be hindered by inadequate attention to the development of the disease and the absence of the necessary therapy readjustment. Particular attention should be placed in the transition from hospital to the territory, avoiding situations of discontinuity or unavailability of operators or unavailability of drugs and hospitals.

6 Right to a free, informed choice

Every person has the right to actively participate in the decisions made regarding pain management.

All decisions involve correct, complete and clear information, taking into account the cultural level of the patient and his/her emotional state. Any therapeutic intervention aimed at relieving the suffering must be agreed upon and regulated according to both quality and intensity, in agreement with the full and informed will of the patient, according to the principles which underpin a good informed consent. Every person has the right to receive prompt and clear answers to questions and have all the time necessary to take the resulting decisions.

7 Rights of children, the elderly and those "without a voice"

Children, the elderly and "sensitive" subjects have the same right not to suffer unnecessary pain; special consideration should be given to their particular status.

The assessment and treatment of pain in children has been ignored for a long time. The medical establishment, in fact, is often happy to transfer to children the knowledge already developed by treating adults rather than undertake research and specific studies, which take into account childhood and its psychological implications.

Fear and anxiety present in all individuals dealing with the disease are different in ill children, in people with mental illnesses or severe mental disabilities and some elderly patients. These patients have difficulty in expressing their pain and therefore its reading is not recorded properly due to the lack of an integrated approach.

8 Right not to suffer pain during invasive and non-invasive diagnostic tests

Anyone having to undergo diagnostic tests, especially those which are invasive, must be treated in such a manner as to prevent episodes of pain.

Some invasive diagnostic exams are not calmly faced when there is fear for the pain they can cause.

2.3 The civic assessment of the Right to avoid unnecessary pain

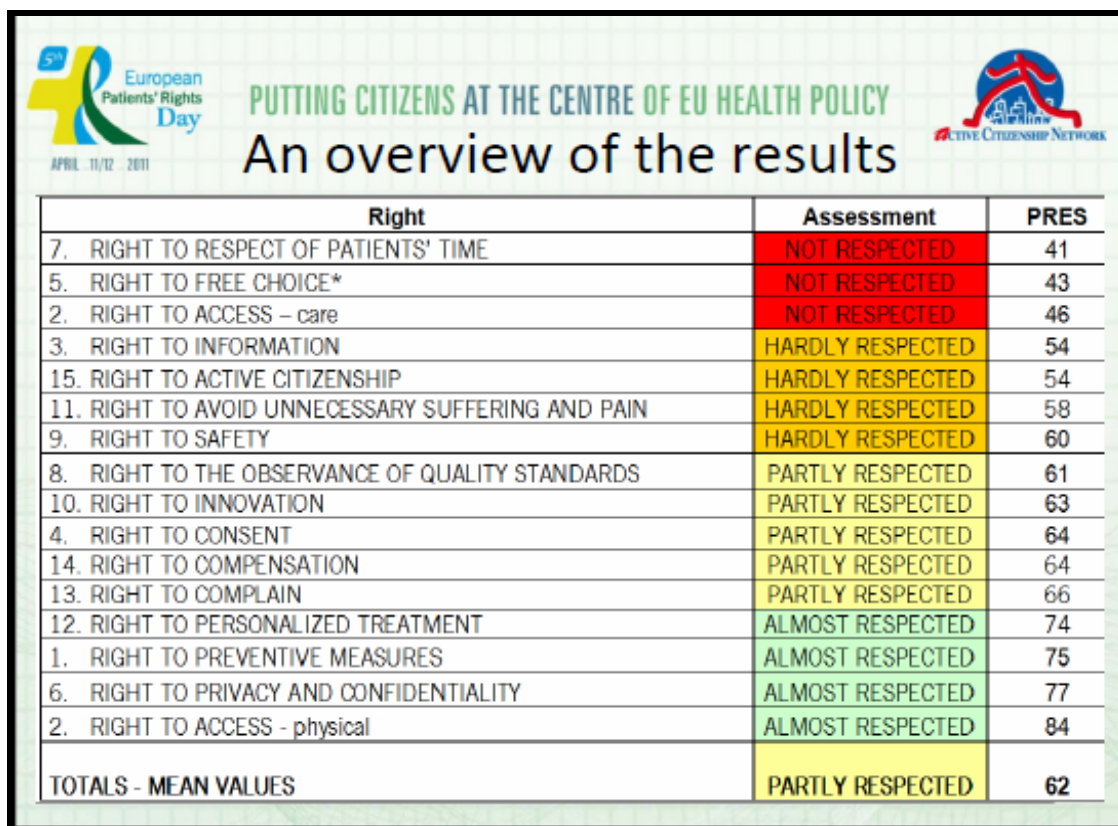
In the past years, ACN have developed two European Assessment programmes on the Patients' Rights Charter according to data collected in 20 European countries. The aim was to put citizens at the centre of health policies, transforming their role from mere targets and users of health services to active citizens participating in health care policymaking and, at the same time, to produce information on the actual implementation of patients' rights at EU level.

Regarding the "Right to avoid unnecessary pain" (one of the rights of the European Charter), the items, the indicators and the information included in the assessment were several and vary:

- at institutional level, the investigation aimed at finding out if the government was preparing national laws and regulations concerning the use of pharmaceutical narcotics.
- at hospital level, managers were asked to forward information regarding pain therapy training for personnel, the use of epidural anaesthesia during labour, patients' pain measurement, and pain therapy service after surgery.
- members of civic organization were requested to report any known violations of rights.

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

The overview of the Report, presented during the 5th European Patients' Rights Day in 2011, shows the following results:



Right	Assessment	PRES
7. RIGHT TO RESPECT OF PATIENTS' TIME	NOT RESPECTED	41
5. RIGHT TO FREE CHOICE*	NOT RESPECTED	43
2. RIGHT TO ACCESS – care	NOT RESPECTED	46
3. RIGHT TO INFORMATION	HARDLY RESPECTED	54
15. RIGHT TO ACTIVE CITIZENSHIP	HARDLY RESPECTED	54
11. RIGHT TO AVOID UNNECESSARY SUFFERING AND PAIN	HARDLY RESPECTED	58
9. RIGHT TO SAFETY	HARDLY RESPECTED	60
8. RIGHT TO THE OBSERVANCE OF QUALITY STANDARDS	PARTLY RESPECTED	61
10. RIGHT TO INNOVATION	PARTLY RESPECTED	63
4. RIGHT TO CONSENT	PARTLY RESPECTED	64
14. RIGHT TO COMPENSATION	PARTLY RESPECTED	64
13. RIGHT TO COMPLAIN	PARTLY RESPECTED	66
12. RIGHT TO PERSONALIZED TREATMENT	ALMOST RESPECTED	74
1. RIGHT TO PREVENTIVE MEASURES	ALMOST RESPECTED	75
6. RIGHT TO PRIVACY AND CONFIDENTIALITY	ALMOST RESPECTED	77
2. RIGHT TO ACCESS - physical	ALMOST RESPECTED	84
TOTALS - MEAN VALUES	PARTLY RESPECTED	62

The above table clearly shows that the right to avoid unnecessary suffering and pain has a very low score:

- the governments of only 4 countries have conducted researches on the existence of national norms that restrict the use of pharmaceutical narcotics and on measures to be adopted to avoid that this might cause unnecessary suffering to patients.
- while, with the few exceptions of some countries, evaluations carried out in hospitals have shown a good level of attention towards patients' pain, frequent cases were found, according to civic organisations, which may be defined as violations of the right to avoid unnecessary suffering and pain. This difference suggests that effective respect for this right is hindered by organizational behaviour and resistance which diminish the efficacy of available services and hospital initiatives.

In general, this unacceptably low score means a lack of respect for this right. Further data support these results:

Right to avoid unnecessary pain

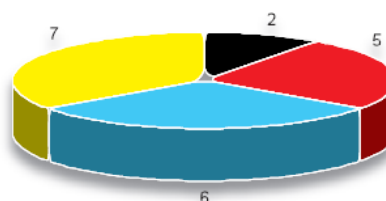
ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- morphine not administered when recommended by the international procedures on severe pain treatment;
- painkillers not administered when needed or after painful treatments;
- lack of measurement of post-surgical pain in the case of all surgical operations;
- presence in national drug control laws or norms of obligations binding the prescription of pharmaceutical narcotics in such a way that might result in the excessive limitation of physician and/or patient access to pain therapy.

Source: Active Citizenship Network, 2011



number of countries with violations regularly found

number of countries with violations frequently found

number of countries with violations rarely found

number of countries with violations occasionally / never found

The very negative result regarding the respect for the rights to avoid unnecessary suffering and pain is clearly of fundamental relevance in the assessment carried out by and with patient organizations committed to reducing unnecessary pain. It sends a precise signal to the civic world and European institutions about the work still to be done: it is a difficult challenge which needs to be faced as a joint effort.

CHAPTER 3 - THE PROJECT: ACTORS, OBJECTIVES AND METHODOLOGY

3.1 Presentation

3.1.1 A collaborative approach: Patients – Citizens – Industry

As previously stated, this is the reason why Patients (Pain Alliance Europe, PAE), Citizens (Active Citizenship Network, ACN) and Industry (Grünenthal GmbH, GRT) have decided to work together in a multi-stakeholder and multi-year project called "Pain Patient Pathway Recommendations Project", of which the present Report is only the first step, although a very important one.

- The project's political framework was designed by Pain Alliance Europe (PAE) representing chronic pain patients in Europe. PAE is the key promoter (or co-promoter with ACN) and operates as the official EU lobby body representing the patients' voice.
- Active Citizenship Network (ACN) was responsible for the scientific design and contents. ACN is the technical expert and consultant and is responsible for supporting the project contents and methodology.
- The pharmaceutical company Grünenthal GmbH (GRT) is responsible for the financial and non-financial support for the performance maximisation and facilitation.

The project includes also a *Steering Committee* with the task to oversee the activities, make strategic decisions and represent the project in an institutional context and in the media. It is composed by representatives from ACN, PAE and Grünenthal GmbH.

The project relies on a *Scientific Committee* with experts supporting the project team in defining the methodology, the technical instruments and the evaluation of the research. The Scientific Committee is composed by the PAE Board.

3.1.2 Objectives and rationale of the project

The principal aims of the project are to:

- have chronic pain recognized as a disease in its own right.
- create a greater awareness of chronic pain.
- promote a European policy on chronic pain.
- reduce the impact of chronic pain in all areas of European society.

The overall rationales are to:

- become a strong European Pain Patient advocacy group by developing concrete (policy) proposals for the improvement of pain management;
- encourage active participation of citizens in European and national public policy-making and the cooperation among many patient organizations, necessary to be heard by the policy makers.

3.1.3 The project's steps

- *Report on the Assessment of the EU Patient Right of Avoiding Unnecessary Suffering and Pain*

Active Citizenship Network and Pain Alliance Europe, with the experience from the association members are a great wealth of information on the condition of patients with chronic pain. They can record the **violation of rights**, the **lack of fair and accessible treatment** and, at the same time, the **good practices** promoted in the various countries. For this reason the first step of the project is an assessment presented in this Report, relating on the respect of unnecessary pain patient rights in Europe.

Develop EU Pain Patient Pathways Recommendations

This Report is not the final objective but a necessary step to understand which concrete proposals against pain can be put forward to European, National and local Institutions in order then to be able to work on the second step of the project: **identify pathways/recommendations against pain** according to the patient's point of view for a good health policy on chronic pain relief.

3.1.4 Geographical impact

The original idea was to carry out the survey in 20 countries, but some difficulties encountered in the management of the project led us to restrict the area of investigation to the following 18, with the promise to expand it to additional countries in a II^o Edition of this survey:

Tab. 3.1 – Geographical impact





Austria	Belgium	Bulgaria
Cyprus	Finland	France ¹²
Germany	Italy	Latvia
Macedonia	Malta	Netherlands
Portugal	Romania	Slovenia
Spain	Sweden	UK

The project has been developed in the above mentioned European countries by national Patients' Associations active in the fight against unnecessary pain. All PAE members were invited to be part of the project as national partners; in the countries where there is no PAE member association, ACN was in charge of finding an equivalent association to carry out the monitoring activities.

The participation of the national associations as project partners was formalized through signing an agreement between each Association and ACN. The agreement will last for the whole course of the project.

3.1.5 What the project is not

Following a precise choice by the Steering and Scientific Committees, this survey does not touch the following points:

-  the interviews will not be addressed to a wide sample of citizens. Therefore, there will not be any indications linking pain to specific segments of the population.
-  it will not deal specifically with cancer pain.
-  it will not deal specifically with centres for pain therapy.
-  this is not a civic audit.

¹² Only for the II^o edition of this civic survey, in October, 2013.

Furthermore, the survey does not link pain to specific pathologies, although these are listed in the first chapter. The reason is precisely to avoid considering pain as a mere symptom and the contribution of this survey goes towards the recognition of chronic pain as a disease in its own right.

3.2 Project Methodology

3.2.1 The "Civic Information" Approach

This report has no statistical value but provides a picture of all main critical areas in the field of non oncologic chronic pain through data collected by civic organisations.

It is therefore an example of civic information.

The methodology is inspired by the method of civic information proposed by many scholars and employed with notable success as a reference model for the work carried out by Cittadinanzattiva in Italy (Wildavsky, 1993; Rubin, 1993; Lamanna - Terzi, 2005; Moro, 1998, 2005a).

Civic information may be defined as the capacity for organized citizens to produce and use information to promote their own policies and participate in public policymaking, in the phase of definition and implementation as well as that of evaluation.

According to this method, when citizens, despite their presumed lack of competence in the public sphere, organize themselves and take action together regarding public policies, they are able to produce and use information deriving from experts and other sources, as well as from their own direct experience with the issue being addressed.

In this project, such a method is implemented by involving civic organizations in the collection of information through interviews with institutions, professionals and patients, which gives the possibility to put into practice the right to participate in the evaluation of services and policies. This could be an innovative aspect of this work, despite difficulties and obstacles that may be encountered such as: possible criticism towards the output since it will not be a statistically representative research; an official dialogue with institutions and health professionals is not always easy.

3.2.2. The sources of information

The survey collected three types of information related to three levels of investigation:


- A.** The first type concerns the degree to which institutional bodies (Ministry of Health) are issuing norms and promoting policies and actions against unnecessary pain. These actions, different in type and in significance (from initiatives already fulfilled to norms with possible gaps in their implementation), show the level of attention for people living with Chronic Pain at a national level.

The source: the Ministry of Health is clearly a qualified source of information and in a position to provide official information about norms, policies, actions and initiatives in this field.

- B.** The second type of information concerns the direct experience of key health professionals who daily manage the care-pathways of Chronic Pain patients and between 3 and 5 of them are selected in each country: doctors, pain specialists, nurses, managers of public and private hospitals.

The sources:

- a) the national representatives of the European Associations of Health professionals, such as:

-  EFIC – The European Federation of IASP® Chapters, a multidisciplinary professional organisation in the field of pain research and medicine.

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- HOPE – European Hospital and Healthcare Federation, international non-profit organisation that representing national public and private hospital associations and hospital owners.
- UEHP – European Union of Private Hospitals
- The National Association of General Practitioners in each country
- The National Association of Nurses in each country

b) an alternative to interviewing the above networks was interviewing the representatives of the main networks which deal with pain management and treatment at national level belonging to the following categories:

- Doctors specialized in the treatment of pain, such as palliative care
- Doctors specialized in the treatment of pain, e.g. experts in pain management
- Nurses
- Psychologists
- Physiotherapists / Rehabilitators
- Family doctors
- Social assistants
- Geriatricians
- Neurologists
- Oncologists
- Paediatricians
- Radiotherapists

We have also collected information regarding the medical centre where the professional interviewed works primarily (hospitals, private clinics, pain-treatment centres, surgeries) these data are treated in accordance with current privacy laws and are not included in this Report: information was used only to help the chronic pain patient associations, ACN and PAE, to bring up to date as regards the project the professionals interviewed.

- C. The third type of information reflects the knowledge civic partner organisations have, with the view that such bodies, given the type of experience and work they are engaged in, may offer a wide range of information on health and the health care system in particular, in connection with serious violations of rights they have become aware of in their role of “protectors” of rights of people living with Chronic Pain.

Sources: National Patients Associations or Citizens organizations dealing with Pain.

The information needed regards actual verifiable cases either directly known by the organisation or by other associations in this field or by specific reports of complaints by patients when their rights have been violated.

The questionnaire for organisations/associations should be completed by the partner organization but if the information needed is not available other sources having direct access and knowledge regarding these data could be used. For this reason, the number of organizations involved is higher than the number of countries. Their list is in the Attachment of this Report.

The Report is integrated by:

- stories of real experiences of people struggling with chronic pain. Civic partner organizations and patient associations have selected stories related to the actual conditions of the citizens suffering because of a pain.
- good practices. A selection of good practices reported both by patient associations and by Ministries of Health.

Stories and good practices do not contribute to the evaluation of the implementation of the state of rights, but are collected and included in order to integrate the reading and interpretation of all other information and to provide a more complete picture of the issue.

The project methodology was presented, shared and finalized during the PAE General Assembly on the 12-13 November 2012.

3.2.3 The Charter of Rights of people living with Chronic Pain

This is a qualitative survey rather than a quantitative one. The main steps for collecting data were:

- A. The survey takes as a reference several aspects of pain linked to rights and principles described in the two Charters previously presented: the "Charter of Rights against unnecessary pain", written in Italy by Cittadinanzattiva and the Charter written in Ireland by Chronic Pain Ireland. In this context, it is important to note that these two countries will hold the Presidency of the European Semester in the years 2013 and 2014 respectively.
- B. Five "factors of evaluation" singled out in the two Charters are listed below with a brief description for each one.

The patient's right to be believed

Each individual has the right to be listened to and believed when reporting personal pain.



The patient's right to have pain treatment and management at the earliest possible stage

Each individual has the right to access the treatment needed to alleviate his/her pain.



The patient's right of access to the best possible technologies and therapies for pain treatment and management

Each individual has the right to receive pain assistance, in observance of the latest, approved quality standards.



The patient's right to be informed about all the pain management options available so that he/she can make the best decisions and choices for his/her wellbeing

Individuals have the right to actively participate in the decisions made regarding their pain management.



The patient's right to live with the least amount of pain possible

Individuals have the right to have their pain alleviated as efficiently and rapidly as possible.

- C. Each factor was subdivided into further sub-factors which could be then identified and measured to ascertain their correspondence to the fundamental parameters necessary to evaluate the implementation level of each right.

Sub-factors were selected on the basis of the following general criteria:

- relevance, or the level of bearing on the questions and problems concerning each right;
- sensitivity, or capacity to register changes (for the better or for the worse);
- precision, or capacity to report in a precise and focused way on the phenomena one intends to register;
- accessibility, or availability without added costs with respect to those provided for in the project budget;

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- concreteness or capacity to register even the most concrete aspects of reality.

All 51 Sub-factors are included in the Attachment in the Report. A database was created for the collection of data at national level obtained through the completion of the questionnaires and is used for data analysis and cross information.

As clearly shown in the following "Synthetic Table of the Rights of people living with Chronic Pain" sub-factors are divided according to factor of evaluation and level of investigation:

Tab. 3.2 - Synthetic Table of the Rights of people living with Chronic Pain

5 factors of evaluation	Organization level		Institutional level		Professional level		Total	
	N° of sub-factor	N° of indicator	N° of sub-factor	N° of indicators	N° of sub-factor	N° of indicator	N° of sub-factor	N° of indicator
The patient's right to be believed	5	21	1	6	4	6	10	33
The patient's right to have pain treated and managed at the earliest possible stage	3	17	3	15	4	6	10	38
The patient's right of access to the best possible technologies and therapies in pain treatment and management	2	7	2	14	3	8	7	29
The patient's right to be informed about all the pain management options available so that he/she can make the best decisions and choices for his/her wellbeing	6	28	3	3	3	5	12	36
The patient's right to live with the least amount of pain possible	5	14	4	13	3	11	12	38
Total N° of indicators	21	87	13	51	17	36	51	174

- D. Each sub-factor was "translated" in a group of indicators detectable through closed-ended questions. All questions refer to the last 12 months.
- E. A value was assigned to each type of expected answer based on a points table¹³.
- F. The value (from 0 to 100) expresses the degree to which the information gathered respects the legitimate expectations held by citizens. This means that for each answer belonging to each of the three types of information described above, 100 will be given whenever it will be verified to be the best situation, which is to say:

- when the **Ministry of Health** gives a positive response regarding the existence of actions, norms and initiatives which, from the citizens' point of view, are particularly important for the implementation of patient rights for people living with Chronic Pain;
- when **professionals** give a positive response regarding the existence of actions, initiatives or services which respect the conditions of the patients;

¹³ If the question is not relevant to you/your organization/your country, please write "N/A" (NOT APPLICABLE). For example: If you ask how many times the chronic pain patient associations have been involved in training initiatives in "centers specialized in the treatment of pain" and these centers do not exist in your country, the answer would be "N/A". Please, explain the reasons/motivations for every one NOT APPLICABLE (N/A) answers.

- when the **patient association and civic partner organizations** do not report having direct knowledge of any violations of patient rights.

3.2.4 Scores and rating

In order to achieve a more “immediate” reading of the results of the investigation and compare those for each country, the partners were assigned an average score for each factor, i.e. a numeric value indicating the distance from the top according to the result obtained:

Tab. 3.3 – Scores and rating

0-40	WEAK
41-70	SUFFICIENT
71-90	GOOD
91-100	EXCELLENT

Each evaluation factor based on the point of view of Ministries, professionals and civic organisations assesses the ability of each country to respect “the Right to avoid unnecessary suffering and pain” according to the following rating.

Tab. 3.4 – Scores and rating

0 – 50	NOT RESPECTED
51 – 60	HARDLY RESPECTED
61 – 70	PARTLY RESPECTED
71 – 90	ALMOST RESPECTED
91 – 100	FULLY RESPECTED

3.2.5 Technical Instruments

According to the methodology it was necessary to produce:

- a questionnaire for the partner organizations divided into:
 - Introduction (a brief presentation of the project, instructions on how to fill in the questionnaire, recommendations, information and contacts of respondents and of the project staff)
 - Part A: Violations of Patient Rights
 - Part B: Comments and Good Practices
 - Part C: Stories of real experience of people struggling with chronic pain
- a questionnaire for professional key individuals divided into:
 - Introduction
 - Part A: Key respondent
 - Part B: Violations of Patient Rights
 - Part C: Summary and open questions
 - Part D: Comments and Good Practices
- a questionnaire for the Ministry of Health divided into:
 - Introduction
 - Part A: Violations of Patient Rights
 - Part B: Comments and Good Practices

- general guidelines for in-depth interviews such as:
 - sociological information related to the interviews with patients, such as age, sex, last job.
 - how long is the patient receiving treatment for pain management?
 - when did pain begin and how long did the patient have to wait for a medical visit?
 - questions on the how the patient is coping with pain.
 - the impact of pain on daily life, etc.
- A grid for the Good Practices:
 - description
 - analysis
 - other information

The questionnaires were designed to be self compiled and to give the possibility to cross them and to make a comparison.

All tools, including the methodology, were discussed and improved in cooperation with PAE and ACN.

The Organization level and Institutional level questionnaires cover the period January/April 2013 whereas the Professional level questionnaire covers the period June/July 2013.

The second edition of the present report will be published within October 2013 and will be integrated with all the information which had not been received when the first edition was published (April 2013).

CHAPTER 4 – PATIENTS' RIGHT TO AVOID UNNECESSARY SUFFERING AND PAIN FROM THE POINT OF VIEW OF NATIONAL INSTITUTIONS

4.1 Difficulty vs cooperation

Nine out of the 18 countries involved in the project have contributed to the collection of data regarding the commitment on fighting pain by National Institutions, specifically the Ministry of Health. Results- if read carefully – unfortunately have not been satisfactory although there are quite interesting general aspects to be noted. Therefore, before analyzing in depth the data collected, it is important to single out the obstacles that have prevented a more significant involvement at an institutional level.

According to the associations of patients who have interacted with their respective Ministries, the obstacles encountered were of three types.

The first and perhaps the most common, is the unwillingness to interact with civil society. This indifference, alongside good intentions not followed by facts, meant that results over a period of three months indicate that this is not a sufficient period of time for some ministries to engage in any investigation promoted by both citizens and patients. Evidently, the malpractice of some politicians and bureaucrats unwilling to communicate with citizens away from election periods is still very difficult to get rid of.

Some examples are for instance the Pelvic Pain Support Network in the UK that has not received any response whatsoever from the Department of Health. And in Belgium, the Ministry of Health has informed patient associations that they are willing to cooperate and will try to deliver the questionnaire as soon as possible, but it was necessary to wait more than three months.

The exception that the survey was supported by a pharmaceutical company seemed a scarcely credible excuse in the light of both the transparency with which the project was presented since its inception and in the light of the explanations given about the role played by each partner. This is what the directors and officers of Austria, Belgium, Bulgaria, Italy, Macedonia, Malta, Portugal, Slovenia and Sweden have perfectly understood and to whom we express our gratitude for the diligence and the spirit of cooperation they have shown.

A second obstacle, perhaps even more alarming than the first, is the lack of a reference point, within the Ministry of Health, directly responsible for the fight against pain. In any case, finding this specific ministerial unit directly involved in the issue has not been easy. Or at least the identification was not simple undertaking. An example is the case of Sweden where the patient's association reported, "it turned out that the Ministry of Health could not answer any of the questions, so the whole questionnaire has been answered by the National Board of Health and Welfare."

Indeed, this lack of addressing the issue was felt to be particularly frustrating by the "Chronic Pain Ireland," association to the point of not wanting to carry out further follow-up surveys in the country.

In fact, **only four ministries out of nine that have responded have an office which deals with the issue**, which says a lot about how fighting pain is still considered of little importance by the "upper echelon" of politics.

But then, if the subject does not find place among ministry officials, will it ever find space among local governments? This cannot be excluded, especially where health care is the responsibility of local authorities. This leads us the third obstacle met by the Ministries when providing us with the required data.

Where there is devolution of health care responsibilities in a federal framework, difficulties in providing data were higher for some specific questions and it was almost impossible to obtain proper answers, as shown in the following tables which provide a detailed statement for each evaluation factor.

In any case, these difficulties can be overcome through goodwill. This was confirmed by the Swedish authorities who admitted that: "In all cases when health care is provided, pain management is central. But local communities are responsible to act according to current laws due to the fact that local governments provide health care according to their own budget. Health care in Sweden is not supplied by the central government; therefore this questionnaire is very hard to answer from a national perspective". Twice as difficult, twice thanks!

In all honesty, it should also be said that these barriers were sometimes multiplied also by the difficulties that some patient associations, which do not work day to day in a national context, have found in delays and difficulties while relating with top ministerial authorities of their country.

4.2 Ministries and fight against pain: strengths and weaknesses

Overall, Sweden is the country with the strongest vocation towards respecting "patient right to avoid unnecessary suffering and pain."

Among the nine countries involved, the public institutions in Sweden followed by those in Italy can be lauded for their efforts in fighting unnecessary pain.

Although not entirely, also Portugal is acting positively whereas the policies of the ministries enacted by the other six countries are absolutely unsatisfactory.

The areas of weakness are the information campaigns aimed at the population at large with the involvement of the patients' associations (promoted only in Italy and Portugal without the involvement of the patients) and - with the exception of Belgium, Italy and Portugal - the almost total lack of vocational training initiatives promoted by the Ministries.

The categories of doctors and health care operators to whom the scarce public resources are mainly destined for professional training and updating are the following (listed in order of funding received):

Tab. 4.1 – Health care professionals

Health care professionals (medical and non medical)	Country where in the last year the Government /Ministry of Health invested funds in professional updating/ training/educational initiatives aimed at pain management professionals
Specialized doctors in the treatment of pain (in palliative care, in pain management)	Belgium, Italy, Portugal
Nurses	Belgium, Italy, Portugal
Psychologists	Belgium, Portugal
Paediatricians	Belgium, Italy
Family doctors	Italy, Portugal
Physiotherapists / Rehabilitators	Belgium
Geriatricians, Neurologists, Oncologists, Radiotherapists	Italy
Social assistants	None

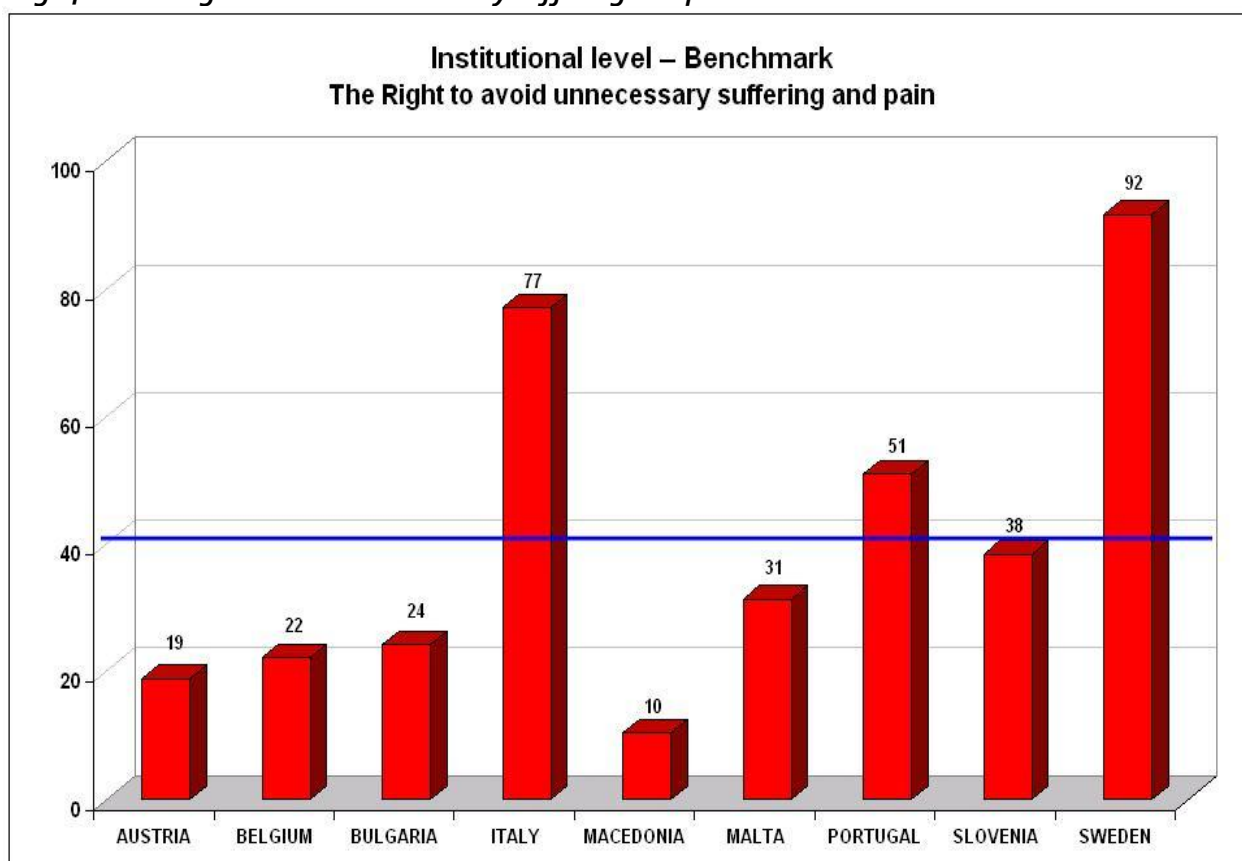
A completely negative fact is that no public institution makes any effort to guarantee a minimum of professional training and updating for chronic pain patients' associations. This is a reverse trend in conflict with the need of investing in self management.

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The hope is that these analyses will focus on the patient's rights and promote greater involvement amongst the partner countries.

In this regard, it should be noted that several Ministries have reported good practices (see relevant chapter), or at least have taken the opportunity to better illustrate their activities.

Fig. 4.1 – The right to avoid unnecessary suffering and pain



The Right to avoid unnecessary suffering and pain is not respected.

The average value, 41 out of 100, is exceeded only by the following 3 countries: Sweden, Italy, and Portugal.

Tab. 4.2 - The right to avoid unnecessary suffering and pain

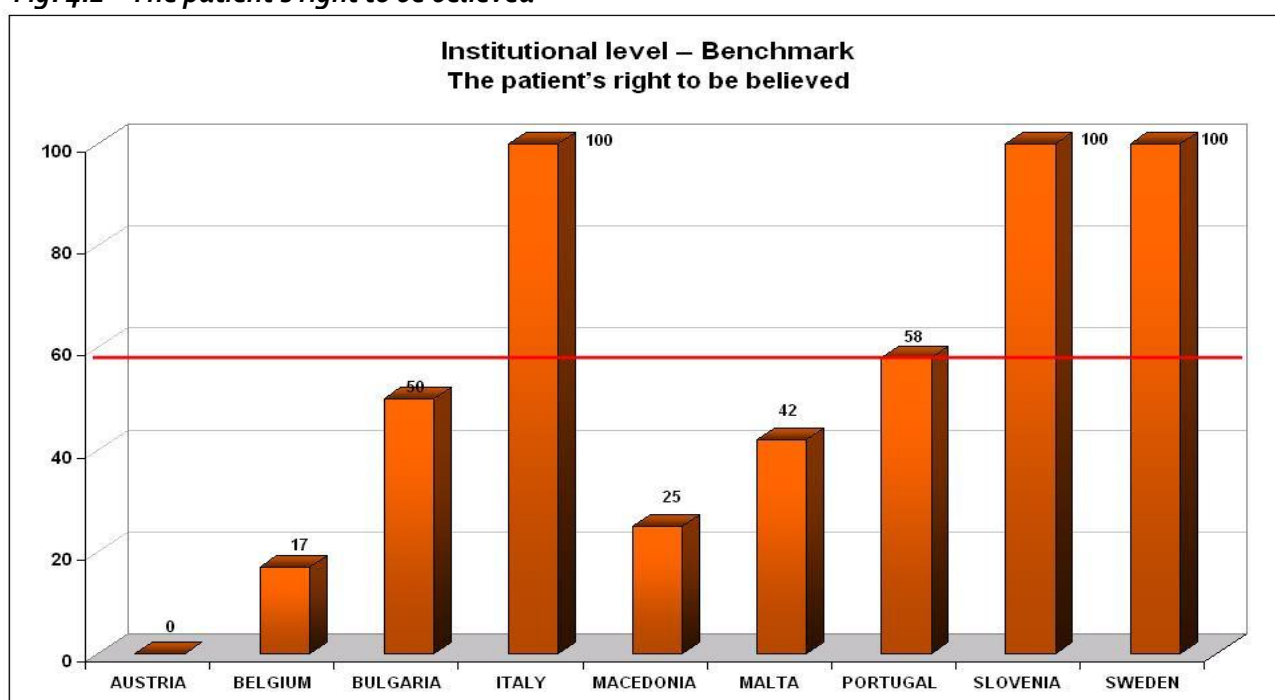
The Right to avoid unnecessary suffering and pain	The patient's right to be believed - score	The patient's right to have pain treated and managed at the earliest possible stage - score	The patient's right of access to the best possible technologies and therapies in pain treatment and management - score	The patient's right to be informed about all the pain management options available so that he can make best decisions and choices for is/her wellbeing - score	The patient's right to live with the least amount of pain possible - score	TOTAL	SCORE	EVALUATION
AUSTRIA	0	57	N/A	N/A	0	57	19	NOT RESPECTED
BELGIUM	17	19	25	0	50	111	22	NOT RESPECTED

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

BULGARIA	50	47	0	0	25	122	24	NOT RESPECTED
ITALY	100	88	38	67	94	385	77	ALMOST RESPECTED
MACEDONIA	25	8	0	0	19	52	10	NOT RESPECTED
MALTA	42	48	0	0	67	157	31	NOT RESPECTED
PORTUGAL	58	47	23	33	94	255	51	HARDLY RESPECTED
SLOVENIA	100	24	0	0	69	192	38	NOT RESPECTED
SWEDEN	100	75	N/A	N/A	100	275	92	FULLY RESPECTED
The Right to avoid unnecessary suffering and pain							41	NOT RESPECTED

4.3 Detailed data from the Ministries of Health

Fig. 4.2 – The patient's right to be believed



The evaluation related to the patient's right to be believed is sufficient.

The average value, 55 out of 100, is exceeded only by the following 4 countries: Sweden, Slovenia, Italy, and Portugal.

Tab. 4.3 - The patient's right to be believed

The patient's right to be believed	1. Measuring pain	TOTAL	SCORE	EVALUATION
AUSTRIA	0	0	0	WEAK

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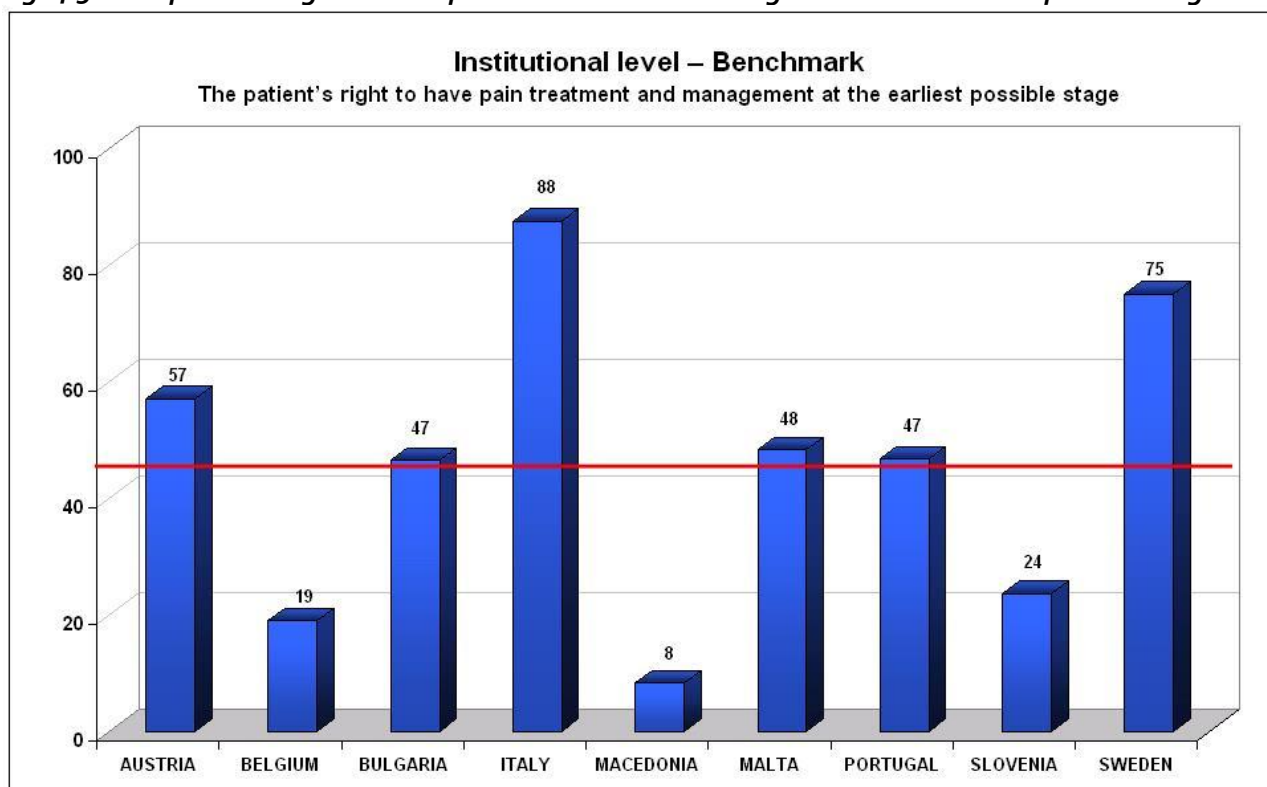
BELGIUM	17	17	17	WEAK
BULGARIA	50	50	50	SUFFICIENT
ITALY	100	100	100	EXCELLENT
MACEDONIA	25	25	25	WEAK
MALTA	42	42	42	SUFFICIENT
PORTUGAL	58	58	58	SUFFICIENT
SLOVENIA	100	100	100	EXCELLENT
SWEDEN	100	100	100	EXCELLENT
The patient's right to be believed			55	SUFFICIENT

The consolidated and widespread practice of pain level assessment allows the evaluation of "The patient's right to be believed" and respected, shows that 3 countries scored top marks.

In particular, the systematic measurement of pain (question no.1) in some cases is explicitly requested by national law while in other it is part of the medical practice. An example of the first case is Slovenia with the "Slovene Patient's Rights Act, Article 39" while Sweden states:

"Sweden does not have any legislation regarding patient rights but does have obligations for the caregivers. Answers are therefore positive since there is Swedish legislation regarding healthcare but there are no specific laws on pain evaluation. Neither are there detailed laws or regulations, but there are norms regarding quality management. Patients are also expected to actively take part in their healthcare".

Fig. 4.3 – The patient's right to have pain treatment and management at the earliest possible stage



The evaluation related to the patient's right to have pain treated and managed at the earliest possible stage is sufficient.

The average value, 46 out of 100, is exceeded by the following 6 countries: Austria, Bulgaria, Italy, Malta, Sweden, and Portugal.

Tab. 4.4 - The patient's right to have pain treatment and management at the earliest possible stage

The patient's right to have pain treated and managed at the earliest possible stage	2. Cost of treatment	3. Restrictive laws	4. To facilitate the access to drugs	TOTAL	SCORE	EVALUATION
AUSTRIA	57	N/A	N/A	57	57	SUFFICIENT
BELGIUM	38	0	N/A	38	19	WEAK
BULGARIA	93	0	N/A	93	47	SUFFICIENT
ITALY	N/A	75	100	175	88	GOOD
MACEDONIA	25	0	0	25	8	WEAK
MALTA	95	0	50	145	48	SUFFICIENT
PORTUGAL	40	0	100	140	47	SUFFICIENT
SLOVENIA	71	0	0	71	24	WEAK
SWEDEN	75	75	N/A	150	75	GOOD
The patient's right to have pain treated and managed at the earliest possible stage					46	SUFFICIENT

As already mentioned, the national health system greatly influences the answers to these questions (maybe some should have been structured differently). In some cases, this also explains the lack of responses. Among the most controversial questions is that about the cost of treatment which confirms how central are the economic issues regarding health policies.

In fact, with reference to question no. 2, "Cost of treatment", Italy specifies that the cost is "generally free but, but being healthcare centred on a federal national system, there is no knowledge of the behaviour of individual regions." No doubt, the fact that the Ministry is not in the position to elaborate regional data does not come out in favour of the ability of the State to keep public health costs under control.

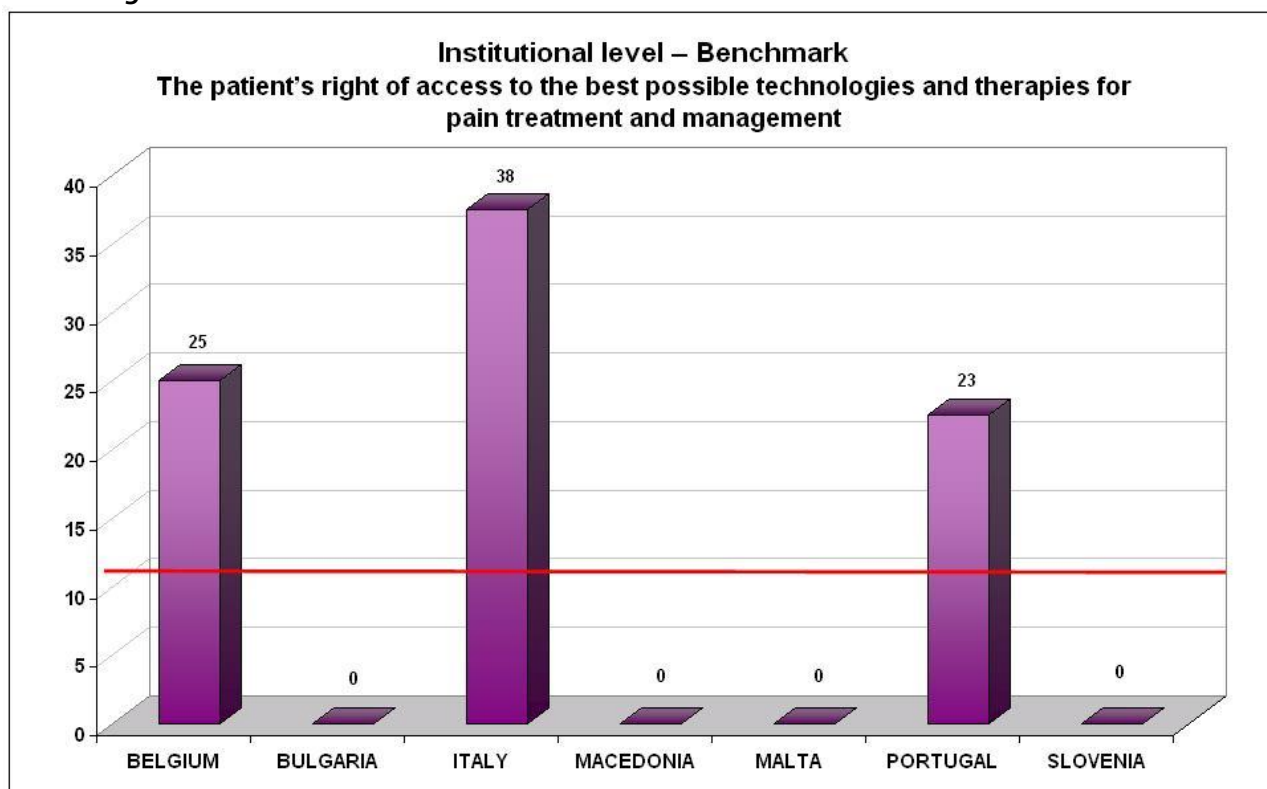
In other cases, answers referred to insurance plans accessed by the patient. In the case of Slovenia, for example, regarding question no. 2, it is noted that "the cost of treatment depends on the insurance as well as on the type of medication/medical apparatus prescribed. What has been stated above determines the extent of the insured person's right to medication/medical apparatus."

Regarding the economical side of the issue, a further point to note is prevention in which investment costs should never be forgotten when it comes to health care. In this case Sweden stresses that "healthcare in Sweden is financed by taxes and a smaller fee is paid by the patient for hospital care and drugs, but there is a "high-cost protection" regulating the expenses for the patient".

In some cases, the absence of modern legislation on this issue prevents knowledge of the phenomenon. An example, relating to question no. 4 "To facilitate the access to drugs", Slovenia indicates that "since guidelines and protocols are not a Ministry of Health area of expertise, we cannot provide answers to this question".

In other cases, however, the score is affected by the relative frequency with which the institutions record this phenomenon. Thus, looking only to question no. 4, the score achieved by Malta is conditioned by the fact that they indicated the situation to occur "only in some cases."

Fig. 4.4 – The patient's right of access to the best possible technologies and therapies for pain treatment and management



The evaluation related to the patient's right of access to the best possible technologies and therapies in pain treatment and management is low.

The average value, 12 out of 100, is exceeded only by the following 3 countries: Belgium, Italy, and Portugal.

Tab. 4.5 - The patient's right of access to the best possible technologies and therapies for pain treatment and management

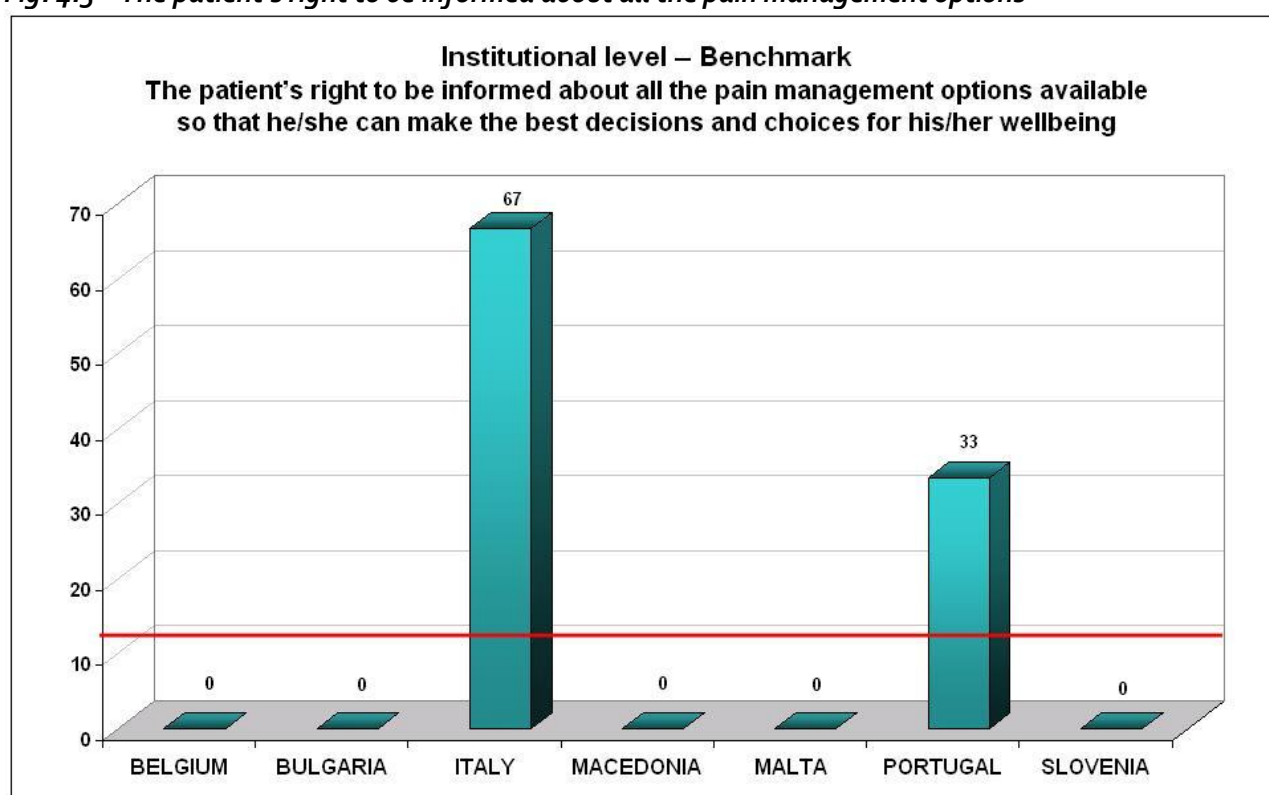
The patient's right of access to the best possible technologies and therapies in pain treatment and management	5. Professional updating/training	6. Training for chronic pain patient associations	TOTAL	SCORE	EVALUATION
AUSTRIA	N/A	N/A	N/A	N/A	N/A
BELGIUM	50	0	50	25	WEAK
BULGARIA	N/A	0	0	0	WEAK
ITALY	75	0	75	38	WEAK
MACEDONIA	0	0	0	0	WEAK

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MALTA	0	0	0	0	WEAK
PORTUGAL	45	0	45	23	WEAK
SLOVENIA	0	0	0	0	WEAK
SWEDEN	N/A	N/A	N/A	N/A	N/A
The patient's right of access to the best possible technologies and therapies in pain treatment and management				12	WEAK

As already mentioned, refresher courses for professionals who daily deal with illness related pain and interact with patients associations are not taken into consideration which inevitably represents a negative factor for the "patient's right of access to the best possible technologies and therapies in pain treatment and management".

Fig. 4.5 – The patient's right to be informed about all the pain management options



The evaluation related to the patient's right to be informed about all the pain management options available is low.

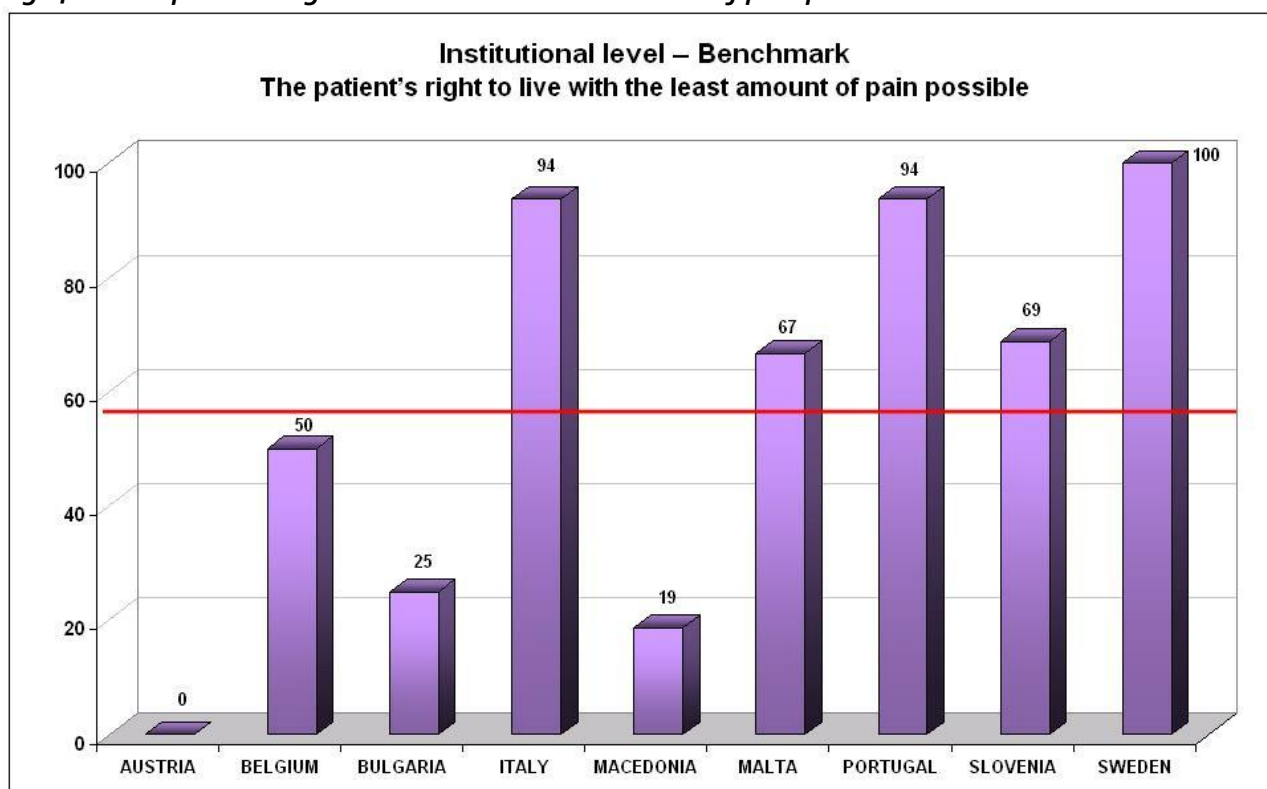
The average value, 14 out of 100, is exceeded by only the following 2 countries: Italy, Portugal.

Tab. 4.6 - The patient's right to be informed about all the pain management options

The patient's right to be informed about all the pain management options available so that he can make best decisions and choices for his wellbeing	7. Communication campaign	8. Involvement of chronic pain patient associations	9. Website	TOTAL	SCORE	EVALUATION
AUSTRIA	N/A	N/A	N/A	N/A	N/A	N/A
BELGIUM	0	N/A	0	0	0	WEAK
BULGARIA	0	N/A	0	0	0	WEAK
ITALY	100	0	100	200	67	SUFFICIENT
MACEDONIA	0	N/A	0	0	0	WEAK
MALTA	0	N/A	0	0	0	WEAK
PORTUGAL	100	0	0	100	33	WEAK
SLOVENIA	0	N/A	0	0	0	WEAK
SWEDEN	N/A	N/A	N/A	N/A	N/A	N/A
The patient's right to be informed about all the pain management options available					14	WEAK

The limited number of financial resources requires a rationalization of health care costs and, inevitably, of the expense of communication and accurate information. Consequently, the factor "The patient's right to be informed about all the pain management options available so that he/she can take the best decisions and choices for his/her wellbeing" is not a priority in the agenda of national governments.

Fig. 4.6 – The patient's right to live with the least amount of pain possible



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The evaluation related to the patient's right to live with the least amount of pain possible is sufficient. The average value, 57 out of 100, is exceeded by only the following 5 countries: Italy, Malta, Portugal, Slovenia, and Sweden.

Tab. 4.7 - The patient's right to live with the least amount of pain possible

The patient's right to live with least amount of pain possible	10. National law	11. Update	12. Dedicated official	13. Socio-economic benefits	TOTAL	SCORE	EVALUATION
AUSTRIA	0	N/A	N/A	0	0	0	WEAK
BELGIUM	0	0	100	100	200	50	SUFFICIENT
BULGARIA	0	0	0	100	100	25	WEAK
ITALY	100	100	100	75	375	94	EXCELLENT
MACEDONIA	0	0	0	75	75	19	WEAK
MALTA	0	100	100	N/A	200	67	SUFFICIENT
PORTUGAL	100	100	100	75	375	94	EXCELLENT
SLOVENIA	100	100	0	75	275	69	SUFFICIENT
SWEDEN	N/A	100	N/A	100	200	100	EXCELLENT
The patient's right to live with least amount of pain possible						57	SUFFICIENT

The objective 'Doing everything possible to help minimise the pain in patients' is mainly achieved in Italy and above all in Sweden since these are the two countries in which decision makers show a greater attention to the issue.

In particular, with reference to question no.11, there are two interesting facts regarding updating methods devised by the countries involved in the project.

Sweden reports that "we have data concerning drug prescriptions and all health care interventions on an individual basis".

For its part Slovenia notes that "the National Institute of Public Health monitors the data on drug prescriptions at national and regional level, according to sex and the age of the patients. Data includes also medication for pain treatment".

4.4 National & regional level: a case study

Data from Portugal were received in two parts: the first from the Regional Health Directorate of the Autonomic Region of Azores and the second from the Directorate General of Health of Portugal. This proves what already pointed out at the beginning of the chapter that is the difficulty to synthesize the information at Country level when the Regional authorities are responsible for health care.

No doubt the Portuguese example suggests a path for further analysis which will allow taking into account also local scenarios and not only the national picture.

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Since there is no doubt about the reliability of the data supplied, it emerges that the Autonomous Region of the Azores represents in Portugal a centre of excellence as regards the fight against unnecessary pain.

Tab. 4.8 – The right to avoid unnecessary suffering and pain

The Right to avoid unnecessary suffering and pain	The patient's right to be believed - score	The patient's right to have pain treated and managed at the earliest possible stage - score	The patient's right of access to the best possible technologies and therapies in pain treatment and management - score	The patient's right to be informed about all the pain management options available so that he/she can make the best decisions and choices for his/her wellbeing - score	The patient's right to live with the least amount of pain possible - score	TOTAL	SCORE	EVALUATION
Autonomous Region of the Azores	100	46	35	67	75	323	65	PARTLY RESPECTED
Portugal	58	47	23	33	94	255	51	HARDLY RESPECTED

Comparison between data in the above table and the values in the following ones clearly shows the good results achieved by the Autonomous Region of the Azores. This indication is further confirmed by the fact that the Portuguese government has presented as an example of good practice the activity carried out in that region (see chapter on good practices).

Furthermore, the fact the Azores were among the first to answer to the questionnaire shows if anything a high level of attention on these issues.

Tab. 4.9 – The patient's right to be believed

The patient's right to be believed	1. Measuring pain	TOTAL	SCORE	EVALUATION
Autonomous Region of the Azores	100	100	100	EXCELLENT
Portugal	58	58	58	SUFFICIENT

Analyzing the data in further detail, the Portuguese Ministry of Health confirms that "there is a national guideline since 2003 for the mandatory register of pain evaluation as the 5th vital sign".

Tab. 4.10 - The patient's right to have pain treated and managed at the earliest possible stage

The patient's right to have pain treated and managed at the earliest possible stage	2. Cost of treatment	3. Restrictive laws	4. To facilitate the access to drugs	TOTAL	SCORE	EVALUATION
Autonomous Region of the Azores	92	0	N/A	92	46	SUFFICIENT
Portugal	40	0	100	140	47	SUFFICIENT

Regarding some data included the second evaluation factor "Cost of treatment" the Ministry of Health indicates that "For some medical conditions, degree of handicap and amount of pension received by the patient medical care is free, including medical devices, rehabilitation and nursing home".

Whereas, as far as the measures to facilitate the access to drugs are concerned "by law there is a reduced co-payment for opiates. Also the General-Directorate of Health has issued several clinical guidelines and recommendations regarding the pain management in different groups of patients: children, elderly, oncologic, neurologic, medical and surgical interventions, etc."

Tab. 4.11 - The patient's right of access to the best possible technologies and therapies in pain treatment and management

The patient's right of access to the best possible technologies and therapies in pain treatment and management	5. Professional updating/training	6. Training for chronic pain patient associations	TOTAL	SCORE	EVALUATION
Autonomous Region of the Azores	70	0	70	35	WEAK
Portugal	45	0	45	23	WEAK

Regarding the third evaluation factor, the Portuguese Ministry of Health has promoted a campaign related to professional training and updating by sending "a screensaver to be installed in computers in hospitals and primary care centres on the importance of evaluation of pain level by healthcare professionals". More than a proper training operation, this seems in fact an initiative to remind all interested parties of the importance of this issue.

Tab. 4.12 - The patient's right to be informed about all the pain management options available

The patient's right to be informed about all the pain management options available so that he can make best decisions and choices for his wellbeing	7. Communication campaign	8. Involvement of chronic pain patient associations	9. Website	TOTAL	SCORE	EVALUATION
Autonomous Region of the Azores	100	100	0	200	67	SUFFICIENT
Portugal	100	0	0	100	33	WEAK

The commitment in the communication campaigns was thus commented by the Portuguese Ministry of Health "last year a TV spot was released to be watched by patients in waiting rooms in hospitals and primary care centres", and regarding the website the Ministry adds that also "the GHD has a dedicated webpage with information about the activities and guidelines for pain management for healthcare professionals".

Tab. 4.13 - The patient's right to live with least amount of pain possible

The patient's right to live with least amount of pain possible	10. National law	11. Update	12. Dedicated official	13. Socio-economic benefits	TOTAL	SCORE	EVALUATION
Autonomous Region of the Azores	100	0	100	100	300	75	GOOD
Portugal	100	100	100	75	375	94	EXCELLENT

With reference to evaluation factor 5 regarding an information collection system allowing the updating of the relevant data, the Portuguese Ministry clarifies that "since the question does not say specifically, we interpreted it as referring to opiates. The information system collecting the data on all dispensed drugs in Portugal is located at the National Drug Agency".

Regarding a specific office dedicated to the issue of pain, the Ministry adds that “at the GHD there is a department that provides clinical and organizational guidelines and another department that houses a dedicated group/program for pain management”.

Regarding socio-economic benefits, the Ministry clarifies that “cash benefits are granted to patients with extreme degrees of handicap”.

Furthermore, the Health Directorate of the Autonomic Region of the Azores explains this region has developed a Programme for Pain Control along the following guiding principles:

1. Subjectivity of pain;
2. Right of Pain-control;
3. Duty of pain control;
4. Pain as the 5th Vital Sign;
5. Multidisciplinary treatment;
6. Differential treatment of pain.

There are Pain Units in every Public Hospital and all patients can be referred to them by their doctor. Hospital Pain Units have multidisciplinary teams who work alongside general practitioners.

Unlike consultations in most medical branches those in Pain Units are free since the Regional Government of the Azores has adopted national laws relating to the non-payment of consultations and health exams by patients suffering from chronic pain.

Training courses for healthcare professionals and other personnel responsible for pain management have been promoted both in hospitals and health centres.

It will not be a coincidence that we will read more about the Azores when dealing with good practices.

CHAPTER 5 - THE PATIENTS' RIGHT TO AVOID UNNECESSARY SUFFERING AND PAIN FROM THE POINT OF VIEW OF THE PATIENTS' ASSOCIATION

5.1 The Right to avoid unnecessary suffering and pain. A disheartening situation

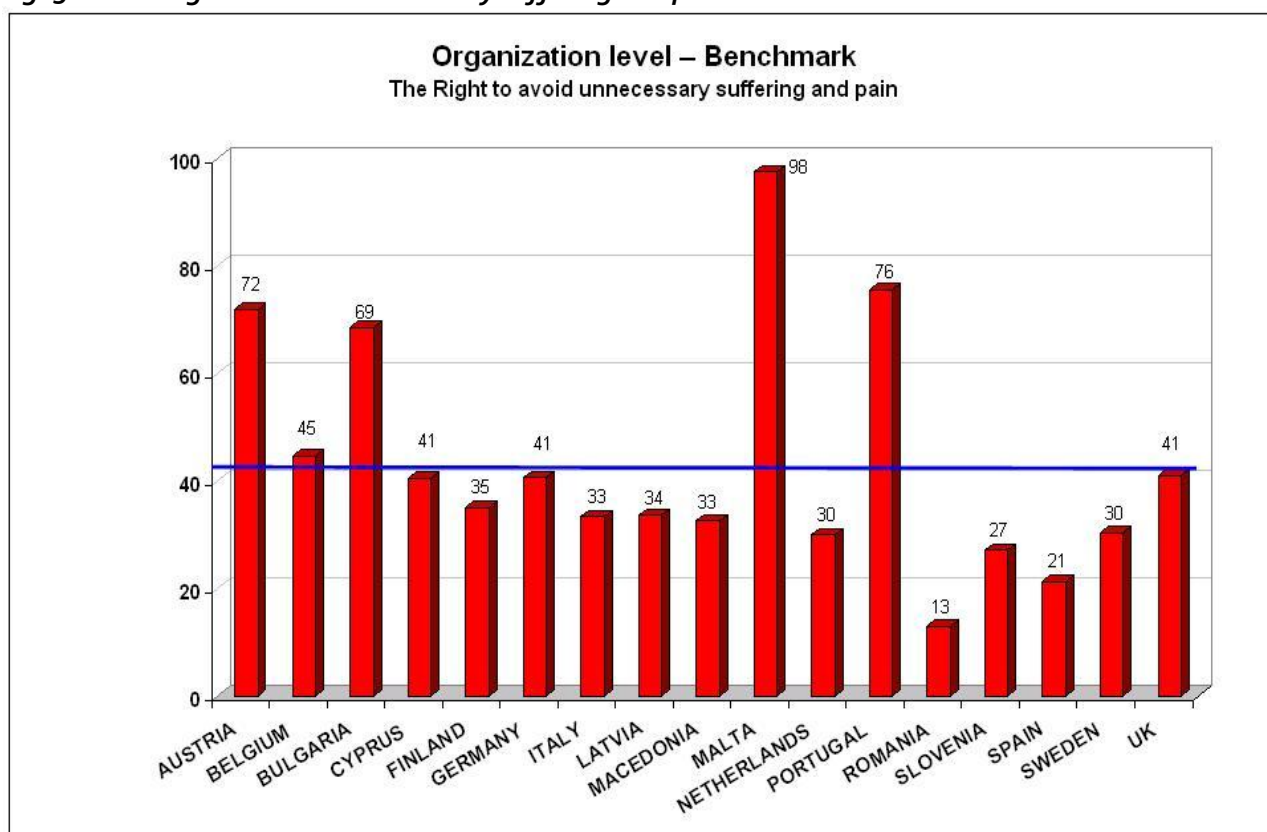
This chapter shows the assessment of the state of chronic pain patients' rights in Europe with the focus on the opinions of chronic pain patients' associations.

From the information received by patients' associations and civic organizations involved in data collection, the picture that emerges is, with few exceptions, somewhat disheartening.

On a daily basis, and considering only the civic point of view, the patients' right to avoid unnecessary suffering and pain is not respected at all.

An exception is Malta, then Austria followed by Portugal and partly Bulgaria. This is certainly not a good sign, but at least it emphasizes once again the need to focus efforts on addressing the issues related to patients with chronic pain.

Fig. 5.1 – The right to avoid unnecessary suffering and pain



The Right to avoid unnecessary suffering and pain is not respected.

The average value, 43 out of 100, is exceeded only by the following 5 countries: Austria, Belgium, Bulgaria, Malta, and Portugal.

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

Tab.5.1 - The Right to avoid unnecessary suffering and pain

The Right to avoid unnecessary suffering and pain	The patient's right to be believed - score	The patient's right to have pain treated and managed at the earliest possible stage - score	The patient's right of access to the best possible technologies and therapies in pain treatment and management - score	The patient's right to be informed about all the pain management options available so that he can make best decisions and choices for is/her wellbeing - score	The patient's right to live with the least amount of pain possible - score	TOTAL	SCORE	EVALUATION
AUSTRIA	60	70	100	70	60	360	72	ALMOST RESPECTED
BELGIUM	34	51	20	70	49	223	45	NOT RESPECTED
BULGARIA	66	37	85	71	84	343	69	PARTLY RESPECTED
CYPRUS	35	28	69	26	46	203	41	NOT RESPECTED
FINLAND	36	38	18	51	32	175	35	NOT RESPECTED
GERMANY	31	59	25	41	47	203	41	NOT RESPECTED
ITALY	31	35	35	44	22	167	33	NOT RESPECTED
LATVIA	32	26	50	22	39	168	34	NOT RESPECTED
MACEDONIA	45	37	4	23	54	163	33	NOT RESPECTED
MALTA	95	100	100	92	100	488	98	FULLY RESPECTED
NETHERLANDS	37	30	22	38	23	150	30	NOT RESPECTED
PORTUGAL	60	80	100	73	66	378	76	ALMOST RESPECTED
ROMANIA	30	9	14	7	5	65	13	NOT RESPECTED
SLOVENIA	28	22	23	33	30	136	27	NOT RESPECTED
SPAIN	40	15	0	16	36	106	21	NOT RESPECTED
SWEDEN	50	46	0	27	29	152	30	NOT RESPECTED
UK	36	36	70	38	26	205	41	NOT RESPECTED
The Right to avoid unnecessary suffering and pain							43	NOT RESPECTED

Of course, it is surprising how Malta represents, overall, a "heaven" compared to other countries. The *Arthritis and Rheumatism Association* of Malta, aware of the results arising from these data, has taken steps to study the situation more in depth by carrying out an additional investigation and a series of visits and reaching the following conclusions:

When checking the questionnaires and going over them with the patients what emerged was that they seemed quite satisfied with the services offered regarding pain management. But the thing is that in Malta

most people would go to their private GP for such things and since they are paying they receive a quick and good service. Also, over the past year, as indicated in the questionnaire for the Ministry of Health, a chronic pain clinic at the hospital has been set up and the doctor in charge is very dedicated and is doing her best to help these patients. Nevertheless, problems are still evident and the same association recognizes that Maltese patients at the moment are suffering mostly due to shortcomings regarding: a) The patient's right of access to the best possible technologies and therapies in pain management; and b) The patient's right to live with the least amount of pain possible".

The above evaluation for each country was determined according to the values shown in the following tables. But how do all these data help?

As with any measurement tool, data are useful to observe the phenomenon and to acquire a better knowledge of it and secondly because they show a real will to take action.

For each country, from a value of 100 (maximum score for the protection of patients' rights) to 0 (no respect) the gap between the best results from the point of view of the patient and the reality of the facts as observed and known by the associations was measured for each indicator.

Conversely, this measurement will be of very little use, or not useful at all if the civic approach to the analysis, which is based on the same survey methodology, is not also taken into account, and if decisions and actions do not follow.

The hope is that this information, complemented with data from other sources, first of all the point of view of specialists as foreseen in the second edition of the present civic survey, can contribute to reach a firm political commitment to put the fight against unnecessary pain at the centre of health policies with a strong position by the EU institutions.

5.2 Detailed data from civic patients' associations

5.2.1. The patient's right to be believed

As expressed in the table below, only 6 countries do not show a negative evaluation on the first of the five evaluation factors, that is to say "the patient's right to be believed."

General Practitioners (family doctors) do not spend enough time listening to chronic pain patients. This is an evident form of malpractice, and is the main fault which hinders "the patients' right to be believed" as shown in the table under "physicians' consultation". This problem is quite frequent in half of the 9 countries, and fairly common in 6.

Among the main aspects to be improved is one which should have top priority and refers to "patient empowerment". In fact, in 7 countries chronic pain patient associations are not involved in the development of chronic pain management for chronic pain patients and/or families, and even when there is a certain level of involvement this is not sufficiently spread out over the territory.

This form of cooperation occurs very often at hospital level in 4 countries and in pain-specialised centres in 1 country, while private clinics are rarely involved.

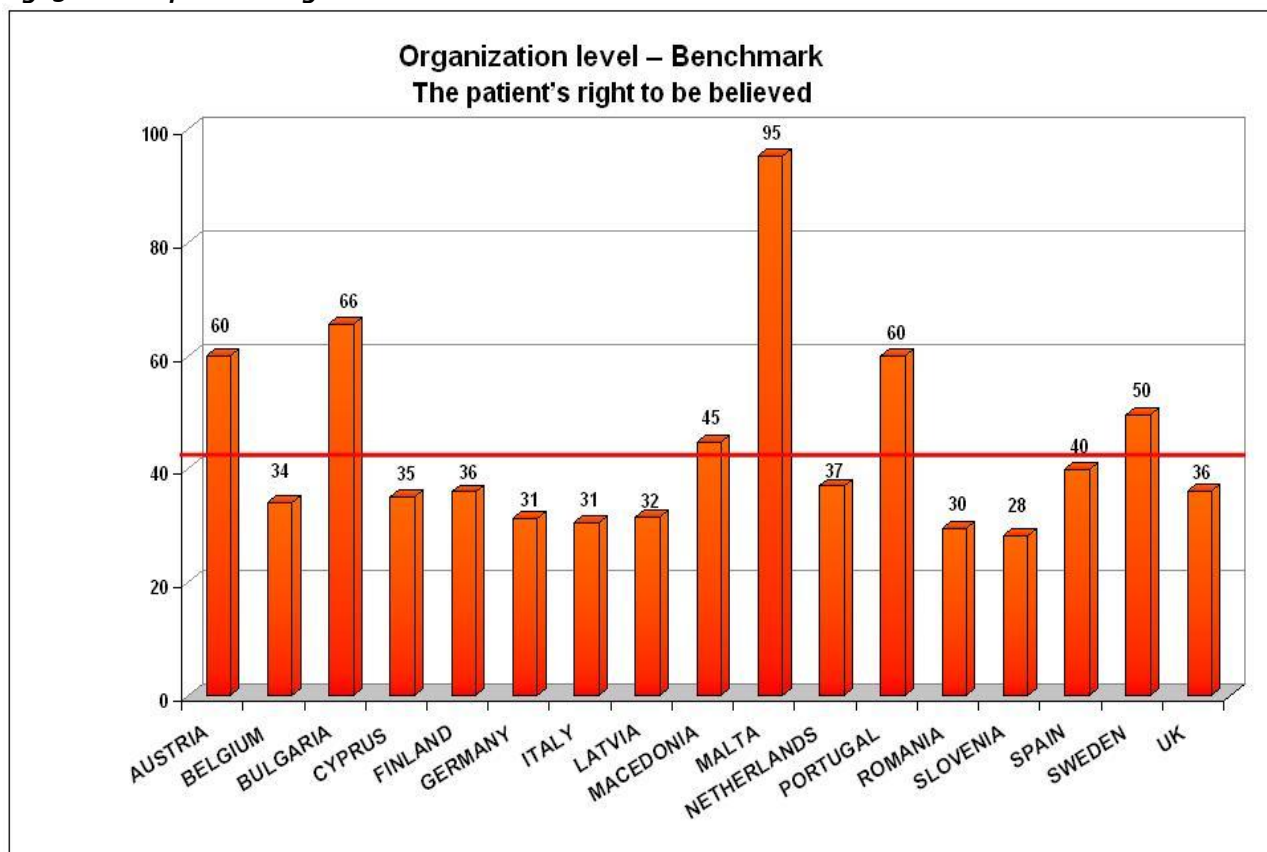
On the positive side, the practice of systematic measurement of pain is now well established and not only restricted to post-surgical pain, although negative exceptions are easier to detect in hospitals rather than in private clinics and in pain-specialised centres.

As far as "physicians' consultation" is concerned, the *Stichting Pijn-Hoop* Association from The Netherlands states that "receiving the right treatment means: patients' complaints should be taken seriously, patient and doctor should find together the best possible solution, respect each other's point of view, supply reliable information, information on available types of medication, timely consultation of pain specialist, tests/screening if possible within one day, complaints should be diagnosed rapidly and should this not be possible, the patient should be given the reason why, provide clear information/communication, unnecessary tests should be avoided".

On "patient empowerment" the above association also adds "where a direct solution cannot be found, patients should be informed of the opportunities offered by patients' organisations on the ways to deal with pain related problems and on the value of interaction with other patients".

In some cases, the patients' associations have added some useful elements to the information requested. For example, with reference to indicator # 5 "violation of the patient's right", the Slovenian *Fibromyalgia Patient Association* has stated that this is a phenomenon which occurs "often in the General Public Clinic." Regarding the same indicator, the Macedonian association *Nora* declared that this phenomenon occurs "sometimes with General Practitioners."

Fig. 5.2 – The patient's right to be believed



The evaluation related to the patient's right to be believed is sufficient.

The average value, 44 out of 100, is exceeded by the following 6 countries: Austria, Bulgaria, Macedonia, Malta, Portugal, and Sweden.

Tab.5.2 - The patient's right to be believed

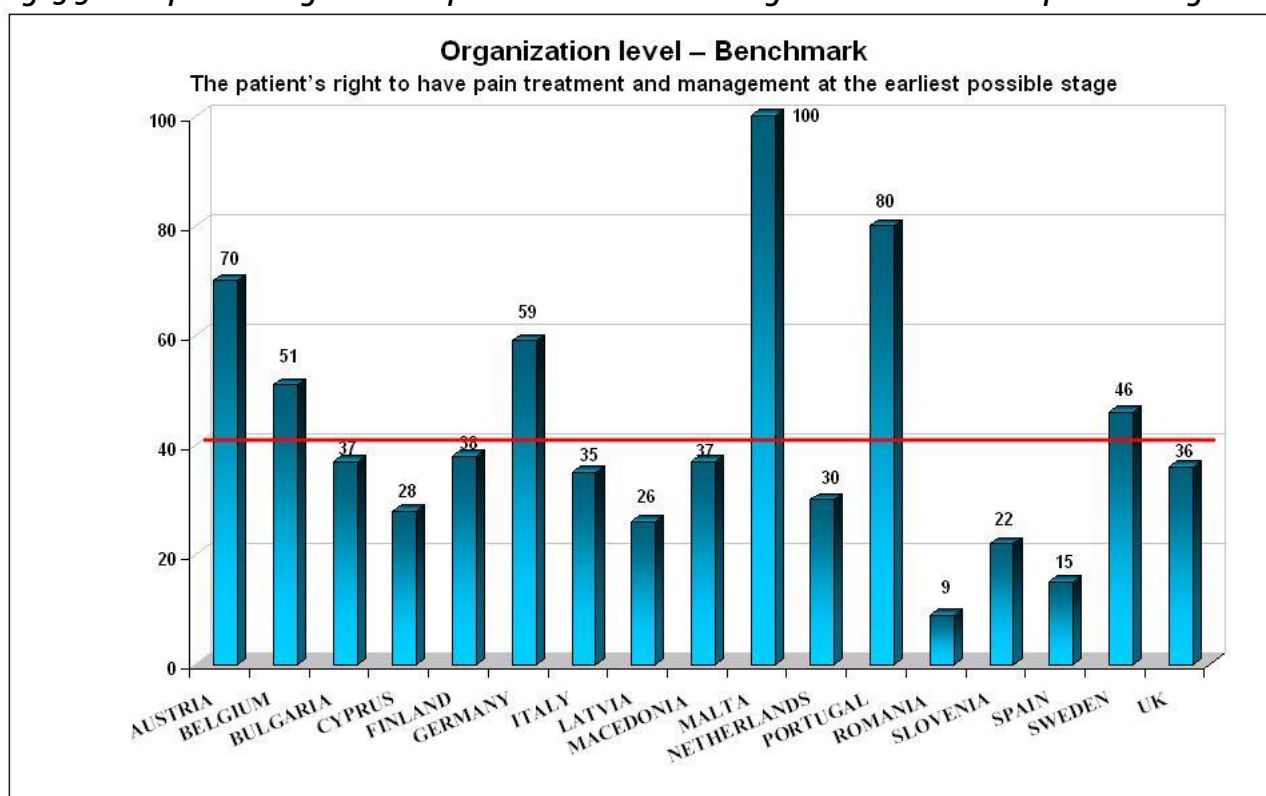
The patient's right to be believed	1. Physicians' consultation	2. Patient empowerment	3. Post-surgical pain	4. Measuring pain	5. Violation of the patient's right	TOTAL	SCORE	EVALUATION
AUSTRIA	40	100	0	100	N/A	240	60	SUFFICIENT
BELGIUM	40	0	40	40	50	170	34	WEAK
BULGARIA	40	53	85	75	75	328	66	SUFFICIENT
CYPRUS	0	0	40	100	36	176	35	WEAK
FINLAND	40	0	40	50	50	180	36	WEAK
GERMANY	0	38	40	23	55	156	31	WEAK
ITALY	0	70	20	25	38	153	31	WEAK
LATVIA	0	0	100	23	35	158	32	WEAK
MACEDONIA	70	58	40	13	43	224	45	SUFFICIENT
MALTA	100	77	100	100	100	477	95	EXCELLENT
NETHERLANDS	0	55	55	27	48	185	37	WEAK
PORTUGAL	40	0	N/A	100	100	240	60	SUFFICIENT
ROMANIA	0	57	35	28	28	148	30	WEAK
SLOVENIA	0	70	20	33	18	141	28	WEAK
SPAIN	0	0	100	100	0	200	40	WEAK
SWEDEN	0	0	100	100	48	248	50	SUFFICIENT
UK	40	50	40	18	33	181	36	WEAK
The patient's right to be believed							44	SUFFICIENT

5.2.2. The patient's right to have pain treated and managed at the earliest possible stage

Regarding the second evaluation factor, "the patient's right to have pain treated and managed at the earliest possible stage", only 6 countries do not show a non-negative general situation.

Associations are aware of the difficulties that chronic pain patients have in accessing treatment because of economic problems and because this treatment is denied when from the chronic pain patient's point of view it seems necessary, although these cases are not very frequent except in a few circumstances.

Fig. 5.3 – The patient's right to have pain treatment and management at the earliest possible stage



The evaluation related to the patient's right to have pain treated and managed at the earliest possible stage is sufficient.

The average value, 42 out of 100, is exceeded only by the following 6 countries: Austria, Belgium, Germany, Malta, Portugal, and Sweden.

Tab.5.3 -The patient's right to have pain treated and managed at the earliest possible stage

The patient's right to have pain treated and managed at the earliest possible stage	6. Painkillers / morphine not administered	7. Economic difficulties	8. Violation of the patient's right	TOTAL	SCORE	EVALUATION
AUSTRIA	N/A	40	100	140	70	SUFFICIENT
BELGIUM	70	43	40	153	51	SUFFICIENT
BULGARIA	40	4	68	112	37	WEAK
CYPRUS	40	7	37	84	28	WEAK
FINLAND	40	34	40	114	38	WEAK
GERMANY	70	51	55	176	59	SUFFICIENT
ITALY	40	41	25	106	35	WEAK
LATVIA	40	4	35	79	26	WEAK
MACEDONIA	40	21	50	111	37	WEAK
MALTA	100	100	100	300	100	EXCELLENT
NETHERLANDS	0	34	55	89	30	WEAK
PORTUGAL	40	100	100	240	80	GOOD

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ROMANIA	0	0	28	28	9	WEAK
SLOVENIA	0	11	55	66	22	WEAK
SPAIN	40	6	0	46	15	WEAK
SWEDEN	40	50	47	137	46	SUFFICIENT
UK	40	34	33	107	36	WEAK
The patient's right to have pain treated and managed at the earliest possible stage					42	SUFFICIENT

In terms of medical expenses, economic difficulties are a recurring phenomenon in 6 countries where drugs and medical devices are to be paid for. In 7 countries even medical rehabilitation must be paid for, as shown in the following table:

In terms of medical expenses, economic difficulties are a recurring phenomenon in 8 countries where a psychological support is to be paid for. In 7 countries even medical rehabilitation and paying travel for treatment abroad must be paid for, as shown in the following table:

Tab.5.4 - Economic difficulties

ECONOMIC DIFFICULTIES	Often	Sometimes	Rarely	Never	N/A
When paying for drugs:	6	8	1	0	0
When paying for medical devices:	6	7	1	0	0
When paying for a medical specialist:	5	6	1	1	1
When paying for medical rehabilitation:	7	3	2	1	1
When paying for hospitalisation:	2	5	3	1	3
When paying for home care:	5	7	0	0	2
When paying for psychological support:	8	5	0	1	0
When paying for home nursing:	6	5	0	0	3
When paying for travel for treatment in home country:	6	5	1	0	2
When paying for paying travel for treatment abroad:	7	2	2	0	4

Data supplied by the associations regarding economic difficulties.

The Belgian association *Vlaamse Pijnliga* says that it is "not easy to indicate the difference between types of cost. We know that psychological support is poorly reimbursed, and we think that few people travel abroad for chronic pain treatment. A study in which we took part in showed that the costs which pose the highest burden on people suffering from chronic illness are drugs, travel costs and home care".

The *Fibromyalgia Association of Sweden* explains why they had to answer Not Applicable to three indicators: "FM normally does not require home care or home nursing. There are no approved provisions for treatment abroad".

This is an example of the high level of attention with which the patients' associations have contributed to the data collection.

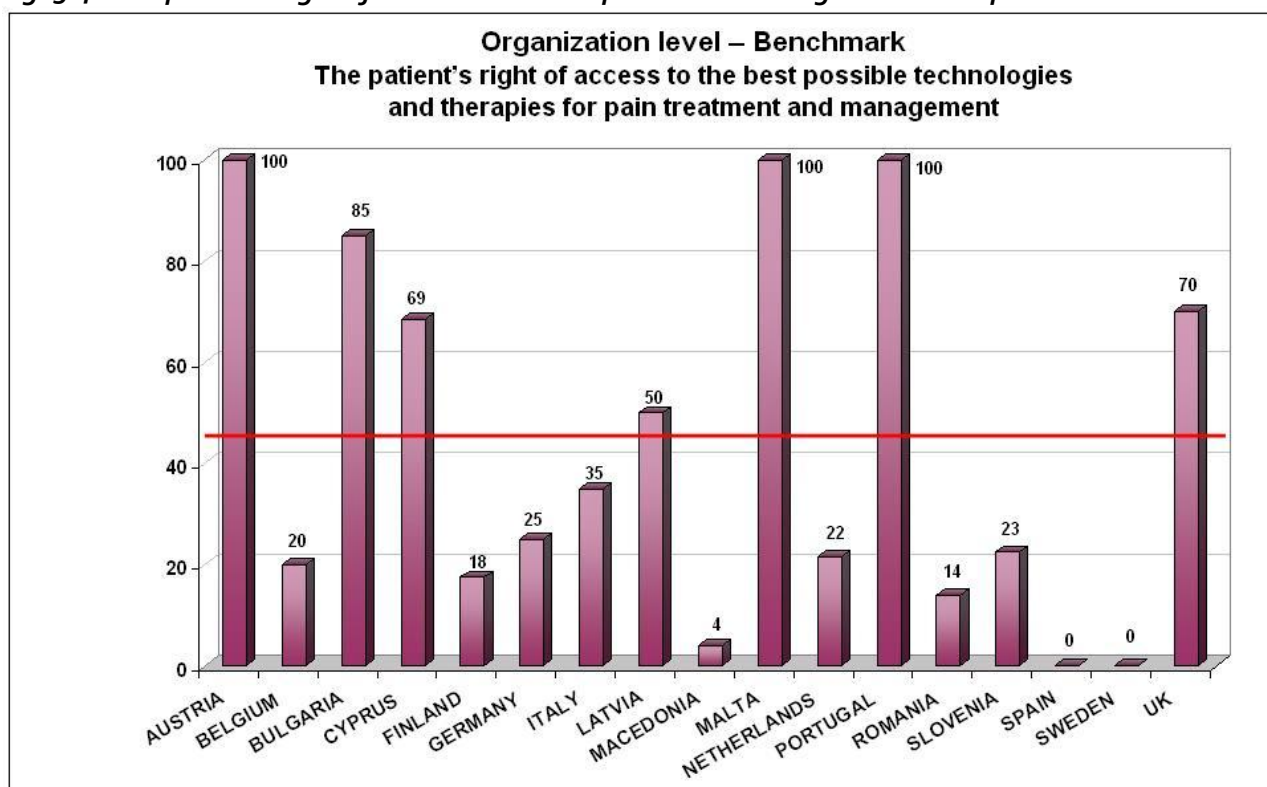
In general, with regards to the violation of the patient's right to have pain treated and managed at the earliest possible stages, as well as the violation of the patient's right of access to the best possible technologies and therapies, the aforementioned Belgian Association frankly admits that it is "not easy to pinpoint the specific problem but there is a more general complaint from the people who face a long quest (years) before finding adequate pain treatment."

5.2.3. The patient's right of access to the best possible technologies and therapies

Regarding the third factor of evaluation there are 7 countries which do not have a wholly negative situation. In any case, the major obstacle to a real respect of "the patient's right of access to the best possible technologies and therapies" is the legislation and/or protocols which prohibit physicians to prescribe the most adequate chronic pain treatment for chronic pain patients: this is evident in 9 countries. For example, this is what Cittadinanzattiva reports "in some occasions, at regional level".

As regards the violation in Italy of the patient's right of access to the best possible technologies and therapies the situation is that: "in some occasion, we find differences in access at regional level, especially in those regions with a high public debt".

Fig. 5.4 - The patient's right of access to the best possible technologies and therapies



The evaluation related to the patient's right of access to the best possible technologies and therapies in pain treatment and management is sufficient.

The average value, 43 out of 100, is exceeded by the following 7 countries: Austria, Bulgaria, Cyprus, Latvia, Malta, Portugal, and the UK.

Tab.5.5 - The patient's right of access to the best possible technologies and therapies

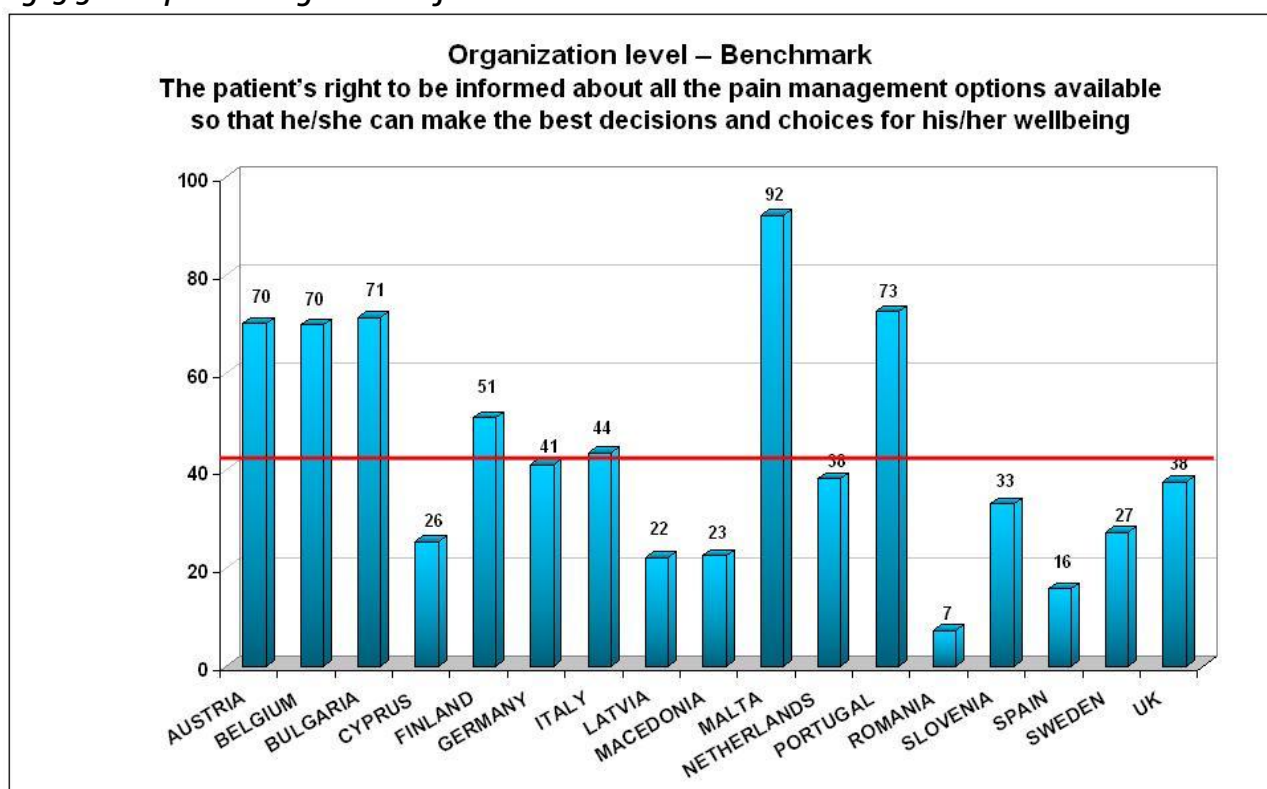
The patient's right of access to the best possible technologies and therapies in pain treatment and management	9. Restrictive laws	10. Violation of the patient's right	TOTAL	SCORE	EVALUATION
AUSTRIA	100	100	200	100	EXCELLENT
BELGIUM	0	40	40	20	WEAK
BULGARIA	100	70	170	85	GOOD
CYPRUS	100	37	137	69	SUFFICIENT
FINLAND	0	35	35	18	WEAK
GERMANY	0	50	50	25	WEAK
ITALY	50	20	70	35	WEAK
LATVIA	100	0	100	50	SUFFICIENT
MACEDONIA	0	8	8	4	WEAK
MALTA	100	100	200	100	EXCELLENT
NETHERLANDS	0	43	43	22	WEAK
PORTUGAL	100	100	200	100	EXCELLENT
ROMANIA	0	28	28	14	WEAK
SLOVENIA	0	45	45	23	WEAK
SPAIN	0	0	0	0	WEAK
SWEDEN	0	0	0	0	WEAK
UK	100	40	140	70	SUFFICIENT
The patient's right of access to the best possible technologies and therapies in pain treatment and management				43	SUFFICIENT

5.2.4. The patient's right to be informed about all the pain management options available so that he/she can make the best decisions and choices for his/her wellbeing

Regarding the fourth factor of evaluation there are 8 countries in which the general situation is not as a whole negative.

What prevents a full respect for the patient's right to be informed about all pain management options available so that patients can take best decisions and choices for their wellbeing is, firstly, the difficulty by chronic pain patients in locating existing services at local level for chronic pain treatment: this situation is common in 10 countries.

Fig. 5.5 - The patient's right to be informed



The evaluation related to the patient's right to be informed about all the pain management options available is sufficient.

The average value, 44 out of 100, is exceeded by the following 6 countries: Austria, Belgium, Bulgaria, Finland, Malta, and Portugal.

Tab.5.6 - The patient's right to be informed

The patient's right to be informed about all the pain management options available so that he can make best decisions and choices for his wellbeing	11. Local services	12. Difficult language	13. Lack of information	14. Alternative care	15. Overuse / abuse drugs	16. Violation of the patient's right	TOTAL	SCORE	EVALUATION
AUSTRIA	40	40	100	100	N/A	N/A	280	70	SUFFICIENT
BELGIUM	100	40	64	100	70	45	419	70	SUFFICIENT
BULGARIA	0	100	100	53	100	75	428	71	GOOD
CYPRUS	40	0	53	9	N/A	N/A	102	26	WEAK
FINLAND	40	40	53	28	100	44	305	51	SUFFICIENT
GERMANY	0	70	54	46	40	37	247	41	SUFFICIENT
ITALY	0	40	38	N/A	100	40	218	44	SUFFICIENT
LATVIA	0	100	10	23	0	0	133	22	WEAK
MACEDONIA	0	40	31	0	40	25	136	23	WEAK
MALTA	100	100	100	53	100	100	553	92	EXCELLENT

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NETHERLANDS	40	40	46	27	40	37	230	38	WEAK
PORTUGAL	40	40	100	100	70	85	435	73	GOOD
ROMANIA	0	0	8	13	0	23	44	7	WEAK
SLOVENIA	0	100	4	0	40	55	199	33	WEAK
SPAIN	0	40	8	9	0	38	95	16	WEAK
SWEDEN	0	40	34	0	40	50	164	27	WEAK
UK	0	100	26	0	100	0	226	38	WEAK
The patient's right to be informed about all the pain management options available								44	SUFFICIENT

A further element that influences negatively, although on a minor scale, is given by cases in which the chronic pain patient complained because, when talking about treatments and therapies, the doctor didn't inform him/her about any alternative care: this situation occurs frequently in 4 countries. In Italy the association Cittadinanzattiva speculates that "maybe we don't receive complaints regarding this issue because citizens don't know that they have this opportunity", thus justifying the lack of a response (N/A). Talking about alternative care the Fibromyalgia Association of Sweden (Sveriges Fibromyalgiförbund) indicates that "Homeopathy, Naturopathy, Osteopathy, Iridology, and Reflexology are not proven scientific methods; therefore doctors are not allowed to inform or recommend these treatments to patients. Regarding Hypnotherapy it depends on who is performing it. It has to be performed by a doctor. In Sweden Physiotherapy is part of the regular medical care offered by the public health care, i.e. it is not regarded as an alternative treatment".

On the subject of alternative care, often in 8 countries doctors do not inform patients about chiropractic and homeopathy, as clearly shown in the following table:

Tab.5.7 - Alternative care

Complementary therapy	Often	Sometimes	Rarely	Never	N/A
Chiropractic:	8	2	2	1	0
Homeopathy:	8	1	2	0	2
Naturopathy:	7	3	0	0	3
Osteopathy:	6	3	2	0	2
Acupuncture:	5	5	3	0	0
Physiotherapy:	4	4	1	3	1
Alternative therapy	Often	Sometimes	Rarely	Never	N/A
Iridology:	9	2	0	0	2
Reflexology (feet reflex therapy):	7	3	0	0	3
Hypnotherapy (mesmerist):	8	4	0	0	1

In a doctor-patient relationship communication is very important, in particular regarding how and what is communicated. In this regard, the first aspect can definitely be improved in the light of the fact that they are still reports on difficulty in understanding medical language.

On the positive side, regarding the second aspect there are no real problems about lack of information, although it is useful to observe in the table below which aspects are less cared for.

Tab.5.8 -Lack of information

LACK OF INFORMATION	Often	Sometimes	Rarely	Never	N/A
What are the procedures for a proper use of medications:	3	6	3	1	0
How to self-manage therapy:	6	5	2	0	0
Duration of treatment:	4	4	5	0	0
Contraindications:	6	5	2	0	0
Side effects:	8	5	0	0	0
Any risk of addiction:	4	6	2	1	1
Type of prescribed drugs (opiates, non-opiates):	4	3	6	0	0
Any changes recommended to patient's behaviour/posture/lifestyle:	4	5	3	1	0
Proper nutrition to follow:	8	0	5	0	0
Any changes recommended in sleeping habits:	5	2	5	1	0

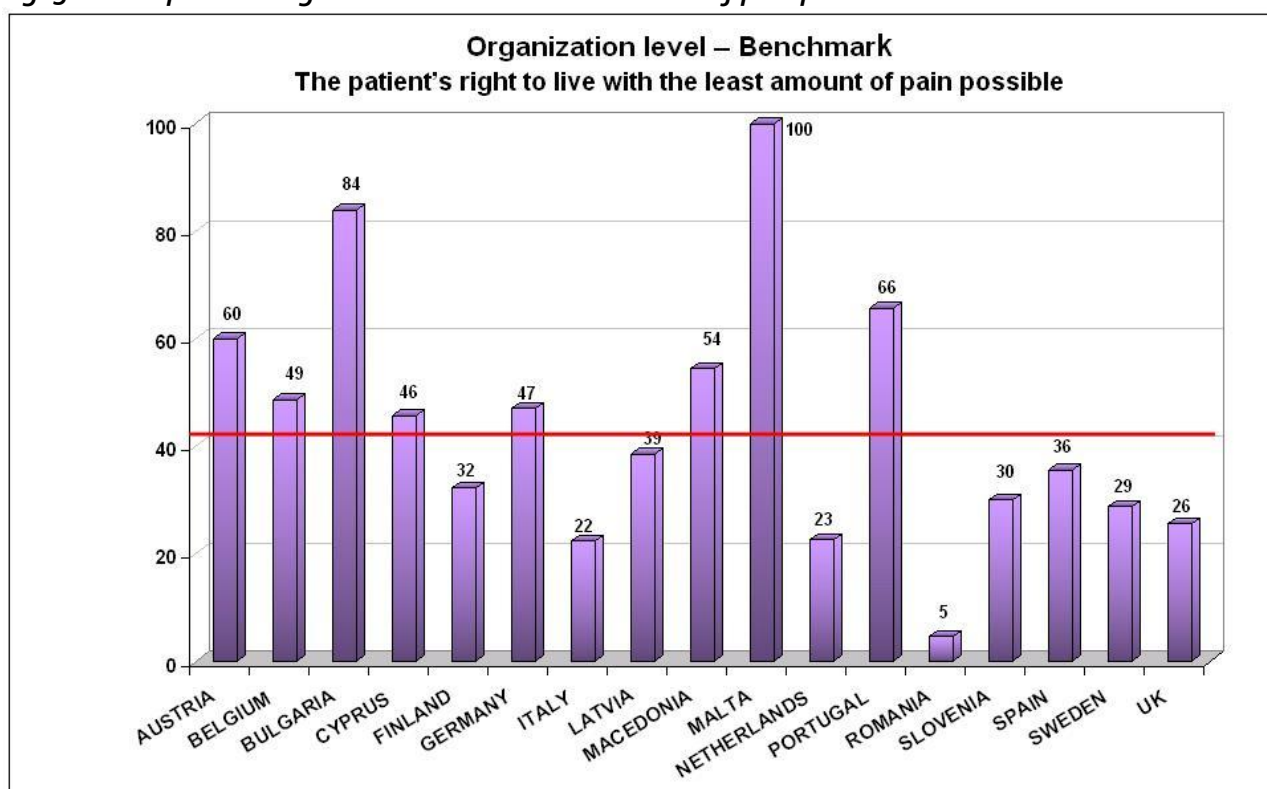
Data from Belgium reports that it is “not easy to indicate the type of information; it is more a general complaint of people not receiving adequate information (or not understanding it). Most notably regarding side-effects and self-management”. The *Pelvic Pain Support Network* from the UK for instance reports that: “in some areas of the country 6 week expert patient programmes are available. These are half day sessions. Managing pain is just one part of the programme which also involves problem solving and action planning. Multidisciplinary pain management programmes are also run in some hospitals. These usually last for several weeks, once or twice a week; they are often not mentioned to patients who could benefit. There is a considerable wait for these and they may also involve travelling a significant distance for the patient”.

5.2.5. The patient's right to live with the least amount of pain possible

Regarding the fifth evaluation factor there are 8 countries which have a positive rating. Two major critical areas which make it difficult to guarantee “the patient's right to live with the least amount of pain possible”:

- waiting for the diagnosis; widespread malpractice in 13 countries. This does not refer to mere waiting lists but to the indefinite time patients, who approached Health Services, had to wait before obtaining the diagnosis applied to his/her chronic pain. Refer to the chapter on patients' testimonies regarding this problem.
- the lack of communication between the GP and specialised doctor about the course of treatment; this situation is very frequent in 8 countries.

Fig. 5.6 - The patient's right to live with the least amount of pain possible



The evaluation related to the patient's right to live with the least amount of pain possible is sufficient. The average value, 44 out of 100, is exceeded by the following 8 countries: Austria, Belgium, Bulgaria, Cyprus, Germany, Macedonia, Malta, and Portugal.

Tab.5.9 -The patient's right to live with the least amount of pain possible

The patient's right to live with least amount of pain possible	17. Waiting for the diagnosis	18. Refusal to prescribe opiates	19. Lack of communication	20. Socio-economic benefits	21. Violation of the patient's right	TOTAL	SCORE	EVALUATION
AUSTRIA	40	100	40	N/A	N/A	180	60	SUFFICIENT
BELGIUM	0	100	40	63	40	243	49	SUFFICIENT
BULGARIA	100	100	100	40	80	420	84	GOOD
CYPRUS	0	N/A	N/A	37	100	137	46	SUFFICIENT
FINLAND	0	35	40	28	58	161	32	WEAK
GERMANY	0	100	0	70	65	235	47	SUFFICIENT
ITALY	0	55	0	20	37	112	22	WEAK
LATVIA	0	70	0	100	23	193	39	WEAK
MACEDONIA	100	55	40	40	37	272	54	SUFFICIENT
MALTA	100	100	100	100	100	500	100	EXCELLENT
NETHERLANDS	0	20	0	40	53	113	23	WEAK
PORTUGAL	0	100	70	78	80	328	66	SUFFICIENT

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ROMANIA	0	0	0	0	23	23	5	WEAK
SLOVENIA	0	40	40	10	60	150	30	WEAK
SPAIN	0	55	0	85	38	178	36	WEAK
SWEDEN	0	55	0	N/A	60	115	29	WEAK
UK	0	40	0	48	40	128	26	WEAK
The patient's right to live with least amount of pain possible							44	SUFFICIENT

As regards lack of communication, data from Sweden show that "We have no legislation regarding communication between GPs and specialists, and this most certainly is something that causes lack of communication". This is an issue which could be dealt with by the civic associations in their recommendations on unnecessary pain.

The Swedish organisations point out on the issue of benefits: "Socio-economic benefits are not granted according to specific illnesses, neither are they denied for the same reason. The issue is regulated by the general degree of disability, and the patient's working capability".

Chronic pain patients' associations know that physicians can refuse to prescribe adequate medication: this occurs in 3 countries for opiates as per following table:

Tab.5.10 -Refusal to prescribe opiates

Medication	Often	Sometimes	Rarely	Never	N/A
Opiates	3	5	2	0	0
Non-opiates	1	5	3	1	0

As regards financial and social support, the recognition of a degree of disability/disability pension is the most common problem, as shown in the following table:

Tab.5.11 - Socio-Economic benefits

Financial support	Often	Sometimes	Rarely	Never	N/A
Cash benefits	4	4	2	2	1
Abstention from paid work/ sick leave payment	2	8	2	1	0
Recognition of a degree of disability/ disability pension	4	7	1	1	0
Social support					
Wheelchairs, chairs, special beds and so on	2	5	4	2	0

Regarding cases where chronic pain patients are excluded from social and/or economical support because of their condition, the Belgian association states that this happens "most notably to people suffering chronic fatigue syndrome".

5.3 Hospitals, private clinics and pain relief centres: where are patients' rights mostly violated?

The associations were requested to indicate in which health care context the violation occurred for each of the five evaluation factors and how often (often, sometimes, rarely, never).

There were six selected contexts: hospitals, private clinics, pain-specialised centres, retirement homes, home care, First Aid Emergency Room. The following table shows the number of occurrences for each case divided by frequency and referring to each of the five evaluation factors.

Considering only hospitalization in the main structures, the pain specialised centres are by far the structures where the rights are less violated whereas in hospitals (mainly publicly run) such violations are more frequent compared to private clinics. These violations are even less frequent in pain specialised centres and to confirm this trend it is sufficient to note how the total of "often & sometimes" in hospitals is higher than that of private clinics and pain-specialised centres.

It must also be said that it has not been easy for the associations to express their synthesis evaluation including so many facets. In this regard, *Fibromyalgia Association of Sweden* has declared that "we have no experience from private clinics, retirement homes or home care", and therefore they could not provide an answer to the relevant questions (N/A).

Tab.5.12 -Where are patients' rights mostly violated?

	The patient's right to be believed	The patient's right to have pain treatment and management at the earliest possible stage	The patient's right of access to the best possible technologies and therapies for pain treatment and management	The patient's right to be informed about all the pain management options available	The patient's right to live with least amount of pain possible	Total
At hospitals:	N° of Countries					
Often	5	6	7	5	2	25
Sometimes	8	5	7	7	8	35
Rarely	1	3	0	2	4	10
Never	0	0	0	0	0	0
N/A	0	0	0	0	0	0
At private clinics:	N° of Countries					
Often	1	0	2	2	0	5
Sometimes	5	5	7	4	5	26
Rarely	4	5	4	5	6	24
Never	1	1	0	1	1	4
N/A	3	3	1	2	2	11
In pain-specialised centres:	N° of Countries					
Often	1	1	3	2	0	7
Sometimes	1	4	4	3	3	15
Rarely	6	5	3	6	6	26
Never	6	4	3	2	4	19

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N/A	0	0	1	1	1	3
At retirement homes:	N° of Countries					
Often	6	4	7	6	4	27
Sometimes	5	7	4	4	5	25
Rarely	1	0	1	1	2	5
Never	0	0	0	0	0	0
N/A	2	3	2	3	3	13
In home care:	N° of Countries					
Often	4	3	4	6	3	20
Sometimes	7	8	6	3	5	29
Rarely	1	0	1	1	3	6
Never	0	0	0	0	1	1
N/A	2	3	3	4	2	14
First Aid Emergency Room:	N° of Countries					
Often	4	4	6	4	5	23
Sometimes	7	4	5	8	3	27
Rarely	2	4	1	0	4	11
Never	1	1	1	2	1	6
N/A	0	1	1	0	1	3

In order to avoid any misunderstanding or manipulation regarding the data concerning public and private structures due to the fact that in absolute value there is a wide gap between negative cases regarding hospitals with those regarding private clinics, it must be clarified that two basic factors should be taken into account to understand the phenomenon:

- civic and patients' associations often have easier access to public structures and therefore know these better than the private ones. To confirm this, the figure regarding "patient empowerment", confirm this situation as well as the experience of different organizations. For example, in Italy, more than 300 local offices of the network of Cittadinanzattiva, which deals with health care, or the Tribunal for Patients' Rights, operate essentially within public structures;
- the profile of the citizen who uses public structures is different from the one regarding the user who prefers to choose a private structure. In fact, whoever chooses as first option the public service might risk having to revert to private structures; but users who chose the private service very rarely revert to the public ones and, in case of malpractice, they find it difficult to immediately turn to a civic or patients' association in order to have their rights protected.

Pain-specialised centres instead, are appreciated and requested also since there are a limited number of them. In fact, as pointed out by the Finnish patients' association *Suomen Kipu ry*, "public authorities are usually tight-fisted when it comes to public hospitals. There is not enough space and there are not enough doctors to take care of all the patients and people are in a waiting list for more or less six months. It is a good practice by some municipalities to re-route patients to private clinics so that they do not have to wait for such a long time. Unfortunately, only few patients can be redirected".

Sveriges Fibromyalgiförbund adds that "generally in Sweden we have health centres which are the first "step" when seeking medical advice/care, thus we don't go to hospitals in the first stage. Hospitals are used for emergency situations, to see specialists (through referrals), to have surgery or for hospitalization.

The majority of our pain-specialised centres are located within hospitals¹⁴, i.e. the service is offered through the public health care system. We have very few private pain-specialised centres”.

In Cyprus, the *European Social Forum Cyprus* says that “ specialised private canters offer good services since all medical help needed such as psychologists, physiotherapists and other professionals can be found there”. It is not a case that the issue of good practices has a whole chapter dedicated to it.

14 Also the Portuguese *Associação Atlântica de Apoio ao Doente Machado-Joseph* informs that “the local hospital has a Pain Unit” but it does give any further details.

CHAPTER 6 - GOOD PRACTICES FROM A CIVIC POINT OF VIEW

6.1 Collection and dissemination of Good Practices

Generally we tend to consider the protection of rights as a type of 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 come across well-known best practices¹⁵.

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 and 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 practice 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 is 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.

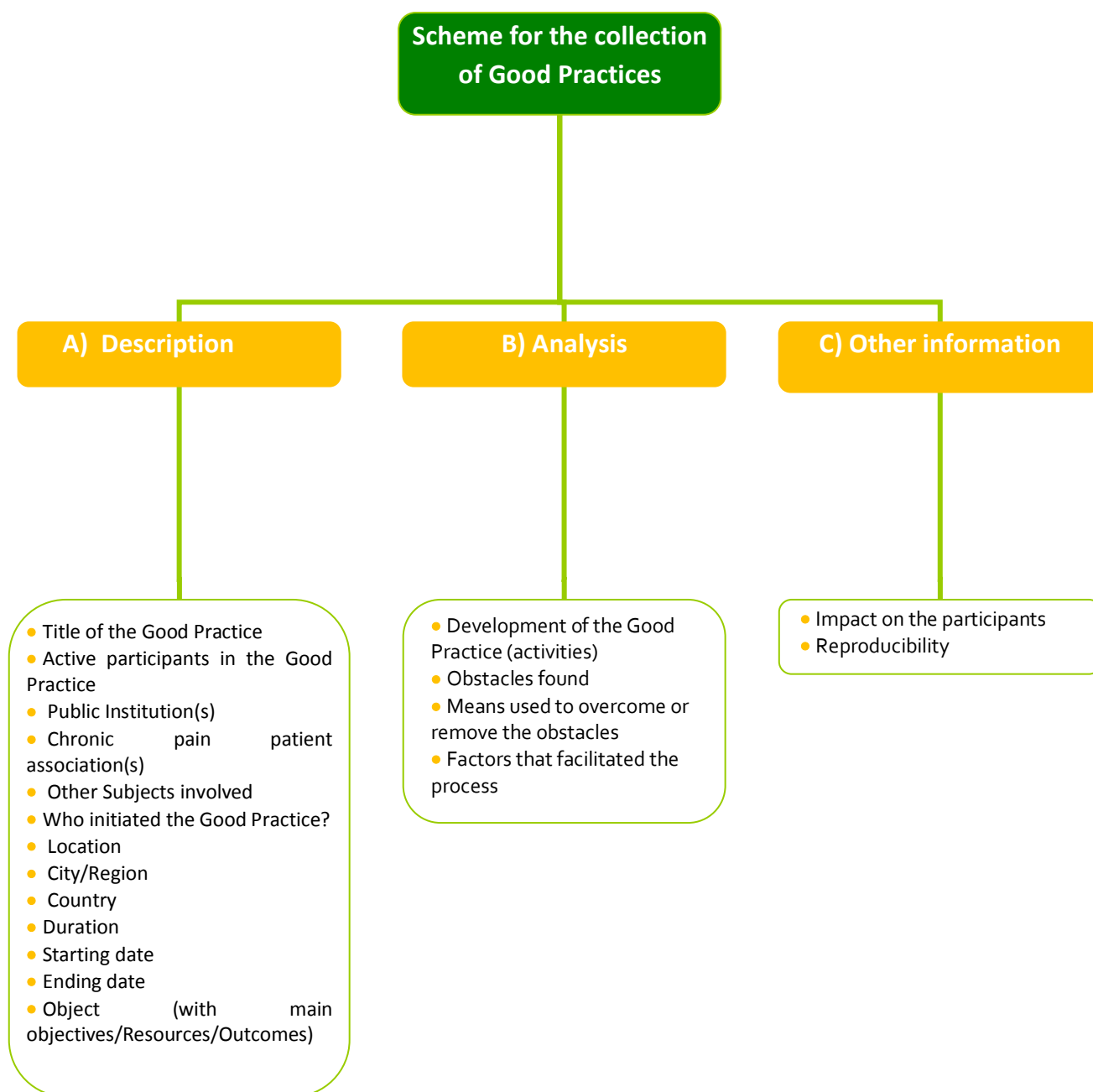
A good practice is defined as such when it also meets the following five requirements:

- 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).

6.2 The scheme suggested for the collection of Good Practices

To facilitate the collection of good practices and to give an order to their description, the following grid divided into three sections was suggested:

¹⁵ Cfr. Giovanni Moro, *Manuale di cittadinanza attiva*, Carocci Editore, 1998.



In most cases, the description of good practice below follows this grid.

Each civic/patient association identified good practices from the point of view of a chronic pain patient who supplied as much detail as possible.

At the same time, also to the Ministries have been asked to point out good practices promoted by the Ministry of Health.

Good practices do not regard clinical treatments or therapies, but how pain management for chronic pain patients is organized, accessed, provided for (by medical or social organizations), paid for and so on. For example: courses in self-management, integration of hospital/community services, involvement of chronic pain patient associations in the organization of services, etc.

It is obvious that the demand to indicate good practices has been considered from patients' associations and associations of civil society (as well as the Ministries) as an opportunity to raise awareness regarding the activities carried out, which is always useful in view of exchanging information and acquiring further knowledge. On the other hand, now more than ever, seeking, encouraging, rewarding and disseminating

good practices answers one of the imperatives of the same mission of many civil society organizations in order to contribute in transforming the individual experiences in a "system" and put citizens at the centre of services.

What is very important is the spirit of human research contributing to the service, the enhancement of the actions of individual citizens, with the aim to create a network of "good operators" which will change things starting from below, in the perspective of subsidiarity, the relationship between citizens and providers of public services.

Furthermore, good practices will be particularly useful for the development of European Pain Patient Pathway Recommendations.

Below is a list of good practices, some of national importance, others with a local impact. Almost all are ongoing activities: some have been completed recently; others are likely to be terminated due to lack of economic resources. This is also a factor to take into account. However, we have also included initiatives to counterbalance those which are still in the start up phase.

The associations from Austria, Cyprus, Macedonia, Malta, Romania, Slovenia and Spain have each reported good practices. Two have come from Belgium, three from The Netherlands and five from Italy. No good practices have been reported by the associations from Finland, Germany, Latvia, Sweden and Portugal.

Furthermore, the Ministries of Austria, Bulgaria, Macedonia and Sweden have not responded to the request of data while we have received information from the Ministries of Health of Belgium, Italy, Malta and Slovenia.

There are three experiences from Portugal (two of which come from the Autonomous Region of the Azores). The lack of experiences is surprising, in particular those from Northern Europe. The Finnish Association, in fact, specifies only that "to overcome or remove the obstacles there should be more freedom for the patients: they should have the right to choose the place of treatment or where to see the doctor."

What is surprising is the statement from Sweden which justifies not reporting any good practice: "We do not know of any good practices regarding pain management. The organization of pain management is not good in our country, and we have no courses on self management. There is no hospital/community involvement that we know of etc".

The justifications from northern Europe are not the only ones, and nor come from the associations. In this regard, the Ministry of Health of the Republic of Macedonia explains why they are unable to report any good practice: "The Ministry of Health did not treat this important issue with the necessary priority. Currently there are no good practices developed by the Ministry of Health on this particular issue". These statements need not be commented upon and clearly explain the difficulties about the subject treated in this civic survey.

6.3 Good practices reported by the Ministries

Good practice reported by the Ministry of Health - Belgium

In the last few years, multiple projects for chronic pain have been launched. Multidisciplinary teams based on a bio-psycho-social model, mainly situated in university centres, were later supplemented with smaller teams based in regional hospitals and with a dedicated algological function. These 'stand alone' projects are nowadays (starting July 1st 2013) merged in a comprehensive policy in which every Belgian hospital should provide a specialised algological service (physician, nurse and psychologist) and be part of a wider network with a supra-regional multidisciplinary team. These networks should develop a uniform and comprehensive policy on pain based on the latest scientific validated evidences and provide an adequate education and structures for continuous sharing of expertise.

In addition, the care of patients with chronic pain problems is in line with a broader health policy for the care of the chronically ill in which are taken different measures for accessibility of care, refunding of treatment, psychological support etc.

Good practice reported by the Ministry of Health - Slovenia

This initiative is called "Local community project: pain management in the Gorenjska region" and involves:

- The Public Hospital Jesenice
- The municipalities of the Upper Gorenjska region
- A hospice
- Home-care Centres
- Professionals

An example of good practice was started with the initiative of a doctor with the support of the Public Hospital Jesenice, where she works. She has been voluntarily offering treatment and support to patients with pain problems as well as providing professional support to local family doctors treating such patients. Since this approach has proved very successful and has helped many patients with chronic pain, as well as their families and GPs, the local authorities decided to support the doctor financially and the Jesenice Hospital to carry out a project. Currently, the project is still in the negotiation stage, but will probably start in the near future.

The project mentioned above is still not fully operative, with a three-year duration, even if the exact dates are still to be decided, and will be carried out in the Upper Gorenjska region.

Should this project be of interest the Ministry will provide details on its realization and results.

Good practice reported by the Ministry of Health - Italy

The Italian Law 30/2010 is a model recognized by everyone. Law 38/2010 is instead a *Hub & Spoke* model (the first regards hospitals and complex cases while the second is territorial) with the inclusion of a third level managed by GPs (General Practitioners).

The guide "*Non più soli nel dolore*" published by the Italian Ministry of Health describes this law as a high innovative instrument which for the first time protects and ensures access to palliative care and to pain therapy to both patients and their families as well as the respect for the patient's dignity and autonomy, a correct response to the need for good health, fairness in access to care, quality of care and its appropriateness to specific individual needs and an adequate health and welfare support. Furthermore, this law indicates a precise path towards humanization of care and provides also recommendations to give shape and substance to the approach to palliative care and pain therapy both for adults and children over the whole country, albeit with some differences in planning, organisation and management.

Law no. 38/2010 simplifies the procedures of access to drugs for pain treatment: GPs can prescribe opiates by simply using the NHS prescription pads.

The patients can therefore be accompanied and supported not only by their family members or by volunteers but also by doctors, health care operators and other professionals specifically trained in palliative care and pain therapy. The measurement and treatment of pain is a duty of all health care operators, therefore under Law no. 38/2010 it is mandatory that pain be detected and registered in the medical record of all hospitalized patients.

Good practice reported by the Ministry of Health - Malta¹⁶

Pain Management striving to decrease waiting time. In fact, over the past year waiting lists in the clinic have decreased by approx 50% (for outpatients).

Good practice reported by the Ministry of Health - Portugal

The Ministry reports as a good practice the "Chronic Pain Patient Association of the Autonomous Region of the Azores Islands, working since 2007" and their activities carried out in particular in the city of Ponta

¹⁶ We apologise with the Ministry of Health of Malta because we have not been able to use all the material sent to us. The low quality document received did not allow us to peruse it properly.

Delgada, promoted by chronic pain patient association since 2007 and planned to last until 2013. The main objectives were adopted by a Chronic Disease Associations Network which is now being registered and are: to identify patients suffering from pain, to inform patients about chronic pain, to inform about resources, to organize public sessions and to cooperate with professionals for better pain treatment and to demand that rights be respected. To begin with, the Ministry has cooperated with four local patients' associations.

As pointed out in chapter 4, we have received information both from the Portuguese Ministry of Health and the Regional Health Directorate of the Autonomous Region of the Azores. The fact that the Portuguese Ministry of Health has publicised the initiatives of the Region of the Azores and that the region has also completed the questionnaire shows that the Azores are leaders in the fight against unnecessary pain. It is therefore worthwhile to examine in depth some of the initiatives promoted by this region.

"Multidisciplinary Pain Units organization" from Portugal – the Autonomous Region of the Azores

Promoted by Public Institutions (Hospitals and Health Centres) and operating since 2001 in the Autonomous Region of the Azores (ARA).

The main objectives are:

1. To reduce the rate of uncontrolled pain in the population of ARA enabling the normalisation of attitudes and orientations that professionals and health care services providers adopt with people suffering from acute or chronic pain, promoting the correct diagnosis and treatment;
2. To improve the quality of life of patients suffering from pain;
3. To rationalize the resources and costs control. All Pain Units have multidisciplinary teams and provide service as follows:

■ UNIT 1 = 5 days a week

■ UNIT 2 = 1 day a week

■ UNIT 3 = 1 day a week

The intent is to organize Palliative Care Teams articulating teamwork between professionals in hospitals and in the community.

Obstacles:

One of the main obstacles was the lack of professionals with specific knowledge and training in pain management. Therefore, training courses for professionals were held alongside activities to increase the level of awareness among people who suffer from chronic pain thus allowing them the most efficient way to consulting and assistance.

Factors which facilitated the process:

1. The experience of having a pain unit in one of the hospitals of ARA (operating since 2001) allowed the development of strategies for a more effective organisation of pain units in the remaining hospitals;
2. The development of a Regional Programme for the control of Pain.

Impact on the participants and reproducibility:

The activities developed allow treating more patients.

The specialists in hospitals, the general practitioners and other healthcare professionals are more aware about the advantages of treating pain.

"Pain education" from Portugal – the Autonomous Region of the Azores

Also this programme is promoted by Public Institutions (Health Centres) and is developed in the Autonomous Region of the Azores (ARA). It is more recent since it started in 2012 and will end in 2013. Also this programme, like the previous one, would benefit from a closer cooperation with chronic pain patient association.

The object is the training in pain treatment for all healthcare professionals and other operators providing care to patients with acute or chronic pain.

Development:

A Pain Doctor Specialist attends meetings and discussions on pain diagnosis, treatment, drugs, clinical cases and referral rules and criteria in local Health Centres. The specialist then provides information on guidelines and related laws for pain patients. Some doctors work at the Pain Units for two or four weeks. The first type of courses has a duration of two/four hours and is attended by all general practitioners, nurses and other technical operators. Currently, over two thirds of the personnel have taken part.

Obstacles:

- The promoting organisation needs more doctors and needs to fight the myths of opiates.
- To overcome the obstacles it needs to continue with training and include information for the public, as well as setting up partnerships with chronic pain associations aiming at a global intervention.

Impact on the participants and reproducibility:

The activities developed allow treating more patients.

The specialists in hospitals, the general practitioners and other healthcare professionals are more aware about the advantages of treating pain.

6.4 Good practices reported by civic/patient associations

"Right care" from the United Kingdom

This is an initiative carried out at national and local level by the chronic pain patient association Pelvic pain Support Network in cooperation with the NHS and public institutions. It began in November 2012 and will end in April 2014. Its objective is to redesign services for pelvic pain linked with gynaecology, urology, gastroenterology, and to improve results and avoid unnecessary procedures/treatments.

Factors that facilitated the process

This will be piloted and evaluated in 2 or 3 geographical areas. Patients will be involved in evaluating and reporting the outcomes.

"Facing pain" from Spain

The initiative is coordinated by SERGAS (Galician Public Health Service) and involves Health professionals and the following chronic pain patient association: REDEFMSFCSQM (Spanish Network of Fibromyalgia, Chronic Fatigue Syndrome and Multiple Quemical Sensitivity), FEGAFIFA (Galician Federation of Fibromyalgia and Chronic Fatigue), LIGA REUMATOLOGICA GALLEGA (Galician League of Rheumatology).

It started in the Galicia Region in October 2011 and is still ongoing.

Thanks to the activity of the Council of Patients, created by the Galician Health Service (SERGAS), patients taken part in the creation of a Commission against Chronic Pain putting forward proposals and attending workshops for patients organized by the Galician School of Patients.

Nowadays, in Galicia, Public Administrators, Health Professionals and Patients Organizations are working together to prepare a standard procedure for Chronic Pain Patients. For this purpose they created a support group that works together on the development of these proceedings and also on the preparation of courses and workshops for Health Care Professionals for Chronic Pain of Primary Health. There is also another group developing the contents of a Chronic Pain workshop for patients.

The methodology consists of meetings, emails and the creation of an interactive work webpage. The main objective is to comply with the Road Map for Attention to Pain approved at the SIP 2011 symposium that was hosted in the EU parliament.

Object:

- To involve the Administration and the Health Professionals in the need to improve the life and care of Chronic Health Patients.
- To implement a protocol and an integrated assistance process.

Resources:

Consulting professionals, meetings, presentation of claims, and use of an integrated work webpage.

Results:

Participation in the elaboration of the procedures for Chronic Pain attention and treatment and not accepting the allegations of the proceedings of FM treatments.

Development:

Attending meetings at the Galician Commission for a Strategy against Chronic Pain. Participate in work groups for the procedure on attention to Chronic Pain on Primary Health. Participation in classes for professionals and patients.

Obstacles:

The Administration has not taken into consideration, in our case, many of our claims about the comprehensive procedure for attention to Fibromyalgia Patients, which has been approved without our consent. We did not have any economic support for travel expenses to attend the meetings.

How obstacles are removed:

Presentation of claims based on research and recent studies and economic support destined to other issues by patient associations.

Factors that facilitated the process:

Keeping in contact with all the people involved through email; exchange and share information; good attitude by health professionals (nurses, psychologists, primary care doctors, pain units nurses and doctors, pharmacists) to work with patients.

Impact on the participants and reproducibility:

This project is ongoing and therefore the coordinator does not have yet all information at hand.

However, Fibromyalgia patients are part of these good practices through their own good practices. In their case, the association represent the Galician Federation of FM and SFC.

"Self-help support group" from Slovenia

This is a joint initiative and an example of partnership among institutions (Specialized public institution for chronic pain) and chronic pain patient association, *Fibromyalgia patient association*. Also the following organizations are actively involved in the programme:

- University Rehabilitation Institute Soča
- Private clinics
- Health resort Laško (thermal spa)
- Professionals (rheumatologist)

This initiative began in June 2012 and is still ongoing in the cities of Brežice, Laško and Ljubljana. The programme consisted of:

- Listening
- Comparison of the problems
- Consultation
- Contacts between institutions and physicians to help with this disease
- Referral to allergies tests
- Advice regarding medication
- Motivation
- Socializing
- Psychological support
- Yoga
- Massages
- Exercise regime: Nordic walking, swimming, stretching

Impact on the participants:

The outcome of the program is overall very positive. Patients were taught to understand and comply with all the instructions; they were given helpful suggestions on how to adapt their lifestyle in order to ease their pain as much as possible through their own efforts. Many of them were able to get back to work after a 14 day program in Laško and five weeks in Ljubljana.

"Dissemination of information about chronic pain and the rights of the patients to be listened to" - Romania

This initiative was coordinated by the *Myeloma Euronet Romania* patient association together with a number of multiple myeloma patients. Public institutions were not involved.

The initiative was developed in the cities of Bucharest and Timisoara from 29 Sept 2012 to 1 Oct 2012.

On September 29, 2012 *Myeloma Euronet Romania* held its third annual conference with the patients. The conference was attended by the Director of Haematological Clinic in Barcelona, a Professor from the University Hospital of Zurich and doctors from hospitals in Bucharest and Timisoara. During this conference a 4 hour session was dedicated to a debate on pain, available treatments, behaviour of doctors and medical staff towards the patients suffering from pain. One of the most critical issues was related to the shortage of pain killers and the non-use of opiates, such as morphine, except for cases of maximum emergency and usually when it is too late for the patients. The patients (about 100 participants) were highly impressed with this session and especially with the experience shared by the professor from the University Hospital of Zurich.

Analysis

In the absence of a national legislation in which pain is recognized as a disease by its own right, the real obstacle to pain management in Romania is the inability of the Ministry of Health to implement programs tailored to alleviate chronic pain, to disseminate information about pain and to make medication available on the market.

The second obstacle is the low Gross Domestic Product (GDP) of the Ministry of Health which makes almost impossible for chronic pain patients to benefit from appropriate medication and equipment.

The third obstacle is the migration of the medical doctors and nurses to other EU countries. Therefore, in the absence of qualified specialists, patients either give up trying or address themselves to less qualified people which sometimes can be very harmful.

In conclusion, in Romania the most important factor is not the right of the patient to be heard and believed as much as the right of the patient to be treated with maximum of professionalism, with the most effective medication and/or treatment at the earliest stage possible. Due to the precarious social economic standards, which range from low salaries of the medical doctors, which prompted them to leave Romania, to one of the lowest GDP allocated to Health, which resulted in shortcomings in proper treatment, proper medication, proper laboratories, the Romanian patients do not yet enjoy what is customarily called in other EU developed countries quality of life.

"Don's struggle alone" from The Netherlands

This is a training programme at national level developed by the *Fibromyalgie en Samenleving F.E.S.*

Its object is to learn how to deal with fibromyalgia by taking part in 6 week meetings attended by patients (also fibromyalgia patients)

Tools:

Causes and recognition; problem solving; communication, sharing experiences; finding a better way of looking at and dealing with the illness.

Results:

Positive thinking, listening to one's body, learning to listen to borders, suggestions from others, learning to talk about the illness in a more positive way.

Development and obstacles:

The development of the right treatment is possible through financial support. The problem for the participants is to obtain care-insurance reimbursements.

How obstacles are removed:

According to professional operators training courses are seen as a positive support to treatment.

Impact on the participants:

The reactions of the participants were very positive. The experience can now help people to face the issue in a positive way. Patients struggle less than in the past and learn to understand better what is wrong with

their body. For some patients it is "wonderful" not having to struggle alone. They also learn how to take benefit from sharing.

Reproducibility:

The training courses are held by professionals. It is a group of enthusiastic people prepared to share experience.

"Tool for quality made by patients" from The Netherlands

The activity is promoted by the chronic pain patient association *Foundation Pijn Platform Nederland* and it started in 2012 at national level and will end in 2014. Other active participants involved are two Public Institutions, five chronic pain patient associations and 8 other subjects.

The main objective is to develop tools for:

1. CQ-index on pain used by professionals to measure quality of treatment;
2. level of quality as described by patients.

Factors that facilitated the process:

- the general practitioner is a very important person for a correct treatment and for the relationships with the other professionals involved. There is a lack of communication and of cooperation between professionals; there is little exchange of information; also finance and timing aspects can lead to problems in the treatment of pain; using the range of choices offered, the use of special treatment centres where specialised personnel is present.
- Cooperation among stakeholders, organisations of patients and professionals
- Using already existing networks, urgent need of finance/grants for a further promotion to patients, professionals and the community as a whole of the issue of pain.
- The role of the government, organisations and institutions is very important for both progress and change.

Impact on the participants:

The distribution of information on journals (*Pijnperiodiek*), newsletters, websites and motivation by sharing experiences could built a better pain –care system for both patients and professionals.

Reproducibility:

In the future tools can be made available to clinics and special pain care centres in order to improve their treatment, for the measurement of the quality of care; also specialised literature on the subject is very important for the updating of health professionals. Know-how and knowledge is important to create a better and greater awareness on the issue of pain.

"Training" from The Netherlands

Since 1992 the foundation *Pijn-Hoop* organises in Lunteren a three day training session with 6-8 participants to teach people suffering from pain to learn how to deal with it. With the supervision of a psychologist and in cooperation with experts participants are taught how to deal with the problem and learn about the effects this has on their daily life.

Obstacles:

Too often unwilling doctors refuse to address patients to pain professionals.

Means used to overcome or remove the obstacles:

Carrying on and not giving up, is the objective for satisfied participants when attending this type of training courses. It is also very important that training is given by experienced personnel.

Factors that facilitated the process:

The ongoing interest for the training is proof of its success

Impact on the participants:

Participants learn that there is more in their life than only pain; they also receive advice on how to go back to a normal life as it was before their illness started.

Reproducibility:

These training sessions can also be offered on request to people with interest outside *Stichting Pijn Hoop* and are open to everybody.

"Self-Management Courses" from Malta

The project is still at development stage. It will start in September 2013 and will end in September 2015. It is promoted at national level by the chronic pain patient association *Arthritis and Rheumatism Association Malta* with the Health Promotion Department as Public Institution.

Main Objectives:

Training of patients in order to achieve a better quality of life.

Resources:

Trained personnel: minimum 2 trainees who in turn will train another 4 members to be able to reach out on a national level. Need of financial assistance to cover training and travelling expenses and tuition fees. To organize training courses on a local level the organization requires funding to cover fees for trainers and to hire venues for the courses.

Outcome:

There will be qualified trainers to teach people how to manage their condition and have a better quality of life, as pain free as possible.

Obstacles:

Main obstacles are the scarcity of financial resources. Possible ways of overcoming this problem would be access to EU funds for training and other EU or local funds for implementation.

Means used to overcome or remove the obstacles:

Good will and communication between the organization and Health Promotion Department based on past experiences and past projects.

Impact:

The objective is that patients with chronic pain will be able to manage their treatment and have a better quality of life.

Reproducibility:

Training is addressed also to other professionals in order to facilitate reaching out to people in need.

"Educative brochures for rheumatic diseases" from Macedonia

This activity is promoted by the chronic pain patient association *Nora* and started in 12.10.2012 in Skopje. The main objective is to educate patients on 10 most common rheumatic and musculoskeletal diseases and their management explained in plain language. Resources came from the pharmaceutical company Roche. The aim is to satisfy patients' need and to increase the level of awareness and self management.

Nora has managed to involve the National Insurance Fund to help distribute informative brochures for the patients in several hospitals in the country. The Brochures explain the nature of a number of diseases seen from the patient's point of view. They also explain which are the DOES and the DON'TS.

Organization of educative workshops for patients with chronic pain and chronic diseases with help from clinical doctors.

Development of Good Practice:

Contact with our organisation member in the USA:

- implementing their good practice brochures
- use of attractive design
- adaptation to our regulations

Obstacles:

Resources for printing

- distribution (right to distribute in public hospitals)
- translation in several (minorities) languages

Means used to overcome or remove the obstacles:

Sponsorship contract with Roche

- several meetings with the head of the health insurance fund and legal advice
- still searching for resources to translate the brochures in languages spoken by minority groups.

- *Factors that facilitated the process:*

University of Michigan, USA

- support from the national electricity production company ELEM
- Head of the department at the Rheumatology Clinic in Skopje
- international league of associations for rheumatology

Impact on the participants:

Better understanding of their disease and origins of chronic pain

- better managing of their disease and symptoms
- better understanding of the physician recommendations
- reduced pain and symptoms
- better compliance with treatment prescribed

Reproducibility:

The chronic pain patient association aims at distributing these brochures to all hospitals in the country which can be updated and reprinted whenever necessary.

"Ospedale Amico" from Italy

Initiative by the Unit Complex (UOC) of Pathophysiology, Pain Management and Palliative Care at the Cardarelli Hospital in Naples, with the involvement of a number of facilities and health professionals (hospital pharmacy, clinical and evaluative epidemiology; civil service project operators; psychologists) as well as civic associations and organizations for the protection of the right to health amongst which the voluntary association Do.No. (No Pain) and Cittadinanzattiva.

The programme focuses on comfort and organizational processes, relationships and taking care of the patient (the elderly and, people suffering from chronic diseases).

The project began in 2003 when in the Campania region the use of opiates was incredibly low because of "myths and misconceptions" on the use of these substances and the culture of the right not to suffer was not so widespread either in hospitals or at regional level. There was a strong resistance from the directors who did not want to invest on resources on structures and personnel for the establishment of Operating Units (OU) for pain management and palliative care, justified by the worsening economic difficulties and the misbelief that the opening of a department for pain therapy would not be beneficial, either economically or regarding care. It was therefore decided to begin a patient work with aim of changing those convictions.

Objectives:

The two main objectives of the initiative were: 1) to identify the cultural problems which, according to the operators involved, were the reason for the low use of opiates. Not being able to interfere with the current legislation, nor on those regarding health policies, it was decided to act on training and on awareness-raising, taking as a case study the hospital and the territory, fielding a number of projects with the purpose of raising the awareness of all physicians to pay more attention to the suffering and a more correct use of analgesic agents, in particular to overcome the cultural resistance present in the medical use of opiates; 2) the second objective was to demonstrate to the hospital managers that terminal cancer patients, in the absence of places dedicated to them, died in intensive care units or intensive care or emergency medicine wards thus improperly occupying beds and using considerable economic resources as well as frequent aggressive treatment and unnecessary diagnostics. On the other hand, we set out to demonstrate that the institution of beds dedicated to pain management and palliative care was not a waste of economic resources, on the contrary this would generate savings and an improvement in the quality of care given, not only to the suffering patient, but to his/her whole family (the patient should no longer be considered a "Monad" but a cell in osmosis with the family).

Methodology

1. Establishment of a working group "team leader" made up of various professionals with the task to design and carry out the project. Regarding the first objective, i.e. the increase in the use of opiates, we have developed a training and awareness-raising programme both intra-hospital and on the territory in order to create greater awareness and attention to the problem of suffering through a series of activities.

2. Carry out a research on the overall consumption of weak and strong opiates in hospital, as well as the type of individual molecules used in the various departments.
3. Definition of the training plan, communication and design of communicational campaigns.
4. Start of communication campaigns.
5. Extension of the activities to the rest of the region.
6. Analysis of medical records of patients who died of malignant tumour in hospital and verification of the place of death.
7. Analysis of cost and revenue for the patients who died of cancer in the hospital.
8. Evaluation of inappropriate admissions of terminally ill patients in non-specialized wards.
9. Evaluation of the cost-effectiveness of U.O.C. Pain Therapy and Palliative Care (TDCP).
10. Evaluation of the quality perceived by patients with chronic benign pain and cancer pain.
11. Customer satisfaction.

Expected results:

- The increase in opiate use at least 30% within 5 years and 60% over a period of 10 years.
- Careful analysis of hospital admissions and especially of the place of death in hospital of terminal cancer patients, who during their last days of life passed away in emergency wards (intensive care, emergency medicine) in order to reduce the number of hospitalization of terminal cancer patients in emergency wards.
- The economic sustainability of a U.O. of TDCP and the savings that would be produced in the system with an improved efficiency and effectiveness of performance. This was expected to prove that the quality of the services offered by this new method (dedicated day-beds) offered a better level of customer satisfaction. All this in order to achieve a reduction in hospital costs by the creation of dedicated day-beds (UO TDCP).

Results achieved:

The results show that the actions taken have contributed to a cultural change in drug prescription by hospital operators with a constant increase per capita of consumption of strong opiates (0.5 in 2003; 0.11 in 2005; 0.31 in 2008; 0.59 in the 2010) and an equal increase per capita in weak opiates (0.21 in 2003, 0.29 in 2005 and 0.51 in 2008, 0.61 in 2010). What emerges is the tip of the iceberg: terminal cancer patients are sent to the ICU, intensive care and emergency medicine where they die. This demonstrates that the creation of dedicated day-beds (UOC TDCP with 7 beds, 2 Day Hospitals, surgery, intra hospital consultations) has led to an increase in correct hospitalization considerably reducing improper admissions in emergency and intensive wards thus contributing in reducing costs and improved assistance. The initiative, which ended in March 2012, has had a local development¹⁷.

"Pain management in non cooperating patients" from Italy

This initiative was launched by the Servizio Formazione and the Comitato Ospedale Senza Dolore (COSD) of the provincial health services of the Autonomous Province of Trento with the involvement of civic associations and organizations for the protection of rights to health, including Cittadinanzattiva (which is part of COSD) and the Alzheimer-Trento Association.

Launched in late October 2009, the initiative will continue throughout 2013, and is a local/regional programme. Pain is very common in hospitalized patients, with high prevalence (43-56%), but only 40-50% of cases are satisfactorily dealt while pain could be controlled in at least 90% of cases. The situation worsens for patients who have less opportunity to assert their rights such as infants, the elderly and people with cognitive disorders. In line with Law no. 38 of 15 March 2010 which sets forth the obligation for the operators to monitor pain and enter it in the patient's medical as well as the training of medical and health personnel, the Comitato Ospedale Territorio Senza Dolore (COTSD) of the health office of the Autonomous Province of Trento (APSS), made up of seven hospital structures and four health districts for a population of about 530,000 inhabitants, has over the years developed an plan for the activities that led to the definition of operational tools for the assessment and recording of pain. The tools now available are:

¹⁷ For further information please consult: www.cittadinanzattiva.it/bp/public/visualizza.php?id_bp=7jsvrr86m1

a slide rule for the detection and measurement of the intensity of pain in children and adults, a card for recording in the patient's medical record the data relating to the assessment and monitoring of pain, guidelines for pain management in hospitalized patients with recommendations to facilitate continuity of care after discharge. With the aim of identifying a suitable tool to detect pain in patients who are not able to express their condition effectively, on request by the Comitato Ospedale Territorio Senza Dolore, in 2008 the Training Department of the APSS has included in its plan continuous training for social and health care integration and for the continuation of care services for the elderly a training project on the management of pain in uncooperative patients. A working group was thus set up, comprising representatives of all professions and organizations involved: doctors, nurses, medical social workers (OSS), physiotherapists and social workers from APSS, Union Provincial Institutions for Assistance (UPIPA) and Provincial Service of Social Policies, which defined a training project for the testing of multiple scales for the assessment and measurement of pain in patients with cognitive impairment. In 2009 a seminar was therefore organised involving health professionals (58 nurses, 2 physiotherapists, 1 speech therapist, 12 hospital doctors and 17 general practitioners) to improve the knowledge of the operators on this specific issue. The project continued in 2010 with the field-testing of two scales (NOPPAIN and PAINAD) for the evaluation of pain in uncooperative patients through the involvement of a group of nurses and OSS Operating Units of Medicine, Neurology and Geriatrics of two hospitals belonging to the a APSS. Following the trial the COTSD identified in the PAINAD the appropriate tool to disseminate throughout the APSS a support for the detection and assessment of pain in uncooperative patients. This was followed by training on clinical content which involved professionals (16 nurses, 6 hospital doctors, 2 general practitioners, 1 physiotherapist, 1 health operator and 2 and social workers). Furthermore, a plan for methodological training (classroom management, setting) is being planned for the same group which will manage the training programmes for the whole province.

Expected results:

The project aims at uniforming all the tools used by the health care teams in the seven hospitals and four health districts, that is the operating methods, tools and languages in the management of pain in uncooperative patients, increase the level of shared responsibility, from assessment to management, providing monitoring of the effectiveness of interventions and continuous re-evaluation thanks to the acquisition of skills in the use of data collection instruments for pain.

Results achieved:

An integrated training programme has been developed which includes the setting up of a pool of professionals both experienced in pain management in uncooperative patients and in the acquisition of methodological and technical tools useful to manage on the job training activities. This will contribute to the training of a greater number of professionals and the creation of a network of subjects involved in the issue through training activities distributed throughout the province. Once training is completed it will be followed by the monitoring of the use of the PAINAD scale with an analysis of its results. This project brings out how continuous training is evermore present in the operational processes and guarantees a wider role starting from the transfer of knowledge ending up with kits contribution to the development of organizational systems and competences. This project has been developed also as a model for other situations since it is integrated between the Health Care Provincial Services and the Provincial Union of Help Care Institutions¹⁸.

"Ospedale senza dolore" from Italy

This initiative began in early September 2008 and was promoted by a public institution such as the Committee Against the pain of Bassano del Grappa with the cooperation of associations for the protection of patients' rights.

Pain is often underestimated also by health professionals. In 2008, the ULSS n. 3 of Bassano del Grappa (VI) (Health Care Office), launched the project "Hospital without pain" which had as its main objective

¹⁸ For further information please consult: www.cittadinanzattiva.it/bp/public/visualizza.php?id_bp=1oabwmj2xp

raising the level of awareness among health professionals on the measurement of pain as a 5th vital parameter.

First the "Recommendations for the management of patients with pain" were set up followed in 2011 by the "Guidelines for the treatment of post-surgery pain" in order to better monitor the consumption of analgesic drugs in the various structures in collaboration with the Pharmaceutical Service.

We expected an increase in the consumption of analgesic drugs as a result of pain being managed more correctly, especially post-surgically. The consumption of both minor and major opiates has significantly increased from 2005 to 2010 as shown by the relevant graphs.

The initiative, which lasted until December 2011, had a local/regional development in Bassano del Grappa/Veneto, benefiting people suffering from chronic diseases, the elderly, people with disabilities and children.

"Progetto V.E.D.U.TA" from Italy

Professional identity and relational network in pain therapy. VEDUTA stands for Core Values against Pain in Care Unit and Assistance. The initiative started in 2013 with the aim of outlining the professional profile of pain therapists and their ability to work on the net in order to identify the underlying existential values, linking the different contexts which operate within the Italian territory. The project is promoted by the ISTUD Foundation and is supported by the Ministry of Health, by the ISAL Foundation and in collaboration with networks of professionals and citizens, including FederDolore, SIIARTI, Change Pain and Cittadinanzattiva.

"Numero Verde contro il dolore" from Italy

This is a free and dedicated telephone number. The ISAL Foundation (the institute which promotes knowledge, research and training in the field of pain therapy) and the Iccrea Bank (the Central Institute of Cooperative Credit) in 2011 set up a call centre to support people affected by chronic pain. This was a worthy initiative even if dedicated only to customers of Cooperative Banks.

"Social companion" from Cyprus

This program is promoted by the European Social Forum Cyprus in Lemesos and it offers personal support (mobility & psychological support and personal assistants) to those people who are in pain and go to hospital unattended.

Many people, mainly elderly subjects, are left alone to face their problems for a number of various reasons. They cannot protect themselves from violations of their rights because they are unaware of their rights and in any case they would not know how to protect them. Therefore, "Social companion" gives advice and offers assistant whenever requested.

Unfortunately this programme will, soon end for financial reasons since it has no support from the state.

"Contact between chronic pain patients within the Vlaamse Pijnliga" from Belgium

This is an activity promoted since 2002 in the Flanders Region by Vlaamse Pijnliga and it is a private organisation with no support from Public Institutions.

Living with chronic pain is a difficult and challenging task. Talking about it can help. The Vlaamse Pijnliga aims to contribute in two ways. Within the member organisations, group meetings organised for people with chronic pain are a central activity. The Vlaamse Pijnliga offers support and inspiration to continue these contacts and organises exchanges between the different organisations.

For more than 10 years now, Vlaamse Pijnliga has learned that these contacts really make a difference for people living with chronic pain. The ability to learn from each other's experiences, the possibility of talking with other people who know what living with chronic pain really means and the knowledge that one is not alone in the struggle with chronic pain are key success factors.

"Multidisciplinary Pain Centres" from Belgium

This was project initiated in 2006 by the National Institute for Health and Disability Insurance (NIHDI), a Public Institution involving 9 hospitals but no chronic pain patient association.

Since 2006, 9 multidisciplinary pain centres in Belgium have been recognised by the NIHDI. Pain patients can be referred to these centres by their GP or treating specialist. Within these centres, doctors cooperate with a number of paramedics, such as physiotherapists, psychologists and pain-specialised nurses. This multidisciplinary approach is highly valued by patients. Moreover, the centres play an important role in the (at social level) recognition of chronic pain.

However, there are still some difficulties. The main problem is without doubt the limited number of patients reached, since there are only 9 centres for the whole of Belgium. Furthermore, within the existing centres resources are limited, which has an impact on the available time and attention patients receive. Cooperation with general practitioners should also be improved. Finally, an important step forwards would be to structurally involve pain patients within these centres. As 'experts by experience' they could play a role in guiding and supporting pain patients that come to the centres for treatment.

"Multimodal Therapy for chronic pain patients" from Austria

In May 2012 in the Klinikum Klagenfurt hospital a unique project was launched for chronic pain patients. Patients are enthusiastic about it.

"I have a completely new and much better quality of life now", reports Christian P. "I had an on-going problem with my intervertebral discs. Since I travelled a lot by car the pain was unbearable" he remembers the many months before he entered therapy in the Klinikum Klagenfurt. Alexander K. was plagued by constant pain "from the right shoulder downwards to the finger tips. In the end I had no strength left in my arm". Since chronic pain can lead to inability to work the consequences of chronic pain are far reaching. "It was incredible. My facial expression became rigid and in the end I was so much in pain that eventually I had to resign from work" Anna K. reports. All three patients have something in common: "We were sent from one doctor to the next - an odyssey which eventually leads to resignation". No therapy produced the desired result - until now.

Individual Coaching

It was the Head of the Department for Anaesthesia and Intensive Care Medicine and the Centre for Interdisciplinary Pain Therapy and Palliative Medicine (ZISOP) in Klinikum Klagenfurt who introduced multimodal pain therapy in spring 2012. Under the motto "More activity, less pain" primarily working peoples could expect an interdisciplinary orientated package of therapies. The Head Physician explains: "Our pain therapy is tailored to individual needs. Chronic pain patients are treated for 4 weeks, those who suffer predominantly with head pain for 2 weeks. Based on a bio-psycho-social pain model a team composed of doctors, psychologists, physiotherapists and doctors of physical medicine - 10 altogether - look after the patients, who in addition receive group training as well as individual instructions. The programme is tailored to the needs of each patient; progress is evaluated on a continual basis.

It is known that the outcome of an all comprising model is more efficient than that achieved in individual modules and therefore leads to a significant reduction of direct and indirect costs.

At the latest after 6 weeks of pain, daily impediments, verification of risk factor for chronic pain ("yellow flags") indication for a multimodal pain therapy should be considered. Patients with headache are examined and guided by the senior physician of the Neurological Department.

Stamina, Strength and Psyche

Physical exercises with the patient consist of 6 hours daily. The morning hours are dedicated to medical training therapy. According to the physiotherapists strength-, stamina- and coordination training as well as water gym, back therapy training, stabilization exercises for the spine as well as sports of all kind are designed to encourage mobility.

The afternoon is dedicated to psychological care: chronic pain to a large extent can be attributed to emotional distress. It is the aim of psychological group therapy to take into account all possible aspects of the disease, because under its progress not only the patients but also their social and environment and their situation at work suffer. In order to promote a change in experiencing pain psychological and stress-

managing strategies, as well as awareness and acceptance exercises are applied. As a result self-control and competence are being raised which enable the patient to return to an active life style.

From Scepticism to Enthusiasm

The feedback from the first groups who finished the multimodal therapy: "In the beginning I was very sceptical and could not imagine it being successful when nothing had helped before to kill my pain. I thought I would stay for one or 2 weeks and then leave", Alexander K. smiles. However, things turned out differently. Already after a few days he noticed that he profited from the therapy. After 4 weeks he was sure that he would recommend the therapy "in all circumstances" to other patients. "Exercising in a group also means you meet new friends and you notice that you are not alone in your misery". "I got a new chance for a better life" adds Christian P. "I intend to keep this newly found of quality life in the future". Oliver U. and Anna K. experience "a great joy in exercising", and "a significant rise in productivity".

Contact between patients and the multimodal team does not end after 4 weeks therapy. Every few weeks the group meets and discusses everyday life situations. If problems and questions arise within this period patients are welcome to contact the team of doctors and nurses.

"Success is lasting"

The feedback of the first groups after four weeks was encouraging. All participants spoke of a lasting success. Integrating the training units in daily life, however, posed a challenge but was successfully overcome by the patients who could now live with reduced pain.

Refresher Day

After half a year the groups are invited to a "refresher day", followed by an option for more refresher days with the purpose of reviewing and complementing the pain mastering strategies received upon discharge.

It is this description of a good practice which contains also a brief feedback from the patients, which allows us to present in the best possible way the contents of the next chapter entirely dedicated to the testimonies of people struggling with chronic pain.

CHAPTER 7 - STORIES OF PEOPLE LIVING WITH CHRONIC PAIN

7.1 Ordinary citizens and chronic pain: similarities and differences

This document includes 19 direct testimonies of people who live with chronic pain. They are everyday stories from Belgium, Finland, Italy, Malta, the Netherlands and the UK (one for each country), Austria, Bulgaria, Macedonia, Spain, Sweden (two for each country), Slovenia (three for each country). There is no contribution from Cyprus, Germany, Latvia, Portugal, Romania and France.

In some cases, the stories are modelled on the suggested scheme, therefore some are interviews and others are real testimonies.

Since the interviews were anonymous, in some cases the right to privacy has been interpreted too strictly, as pointed out by one of the Dutch associations: "*Since Stichting Pijn-Hoop respects the Law on Privacy in the Netherlands we are unable to present personal stories*"¹⁹. Luckily, another Dutch association, Fibromyalgie en Samenleving EDF, has interpreted it in the correct manner, providing interesting data. First names are indicated only with the consent of the respondents and the right to privacy is guaranteed.

The stories show some common elements such as the effects of both objective and subjective relapses caused by pain, and especially how living with pain is firstly a personal and secondly a social experience.

The testimonies were from ordinary citizens, many of whom have been "forced" into early retirement although still of working-age (respondents were mainly between 40 and 60 years of age, but there are also some in their thirties): civil servants, the logistics engineers, pump attendants, teachers, housewives, gardeners, administrative assistants, court clerks.

7.2 The suggested scheme for the collection of data

Each civic/patient association identified and interviewed citizens suffering from a chronic condition and whose rights have been seriously violated.

Relevant data collected:

- **Personal data:** gender, age, marital status, profession.
- After the first signs of pain, **how long did he/she wait** (i.e. days/weeks/months/years) before deciding to consult a physician, or before being referred to a specialized centre for the treatment of chronic pain, etc.
- If he/she has waited months/years, **why so long?** (i.e. because pain is thought to be part of existence, so it must be accepted; the problem was underestimated; use of self-medication with painkillers; family doctor was not consulted, etc.)
- **How long has he/she has been undergoing treatment** for chronic pain management? (i.e. less than 6 months; more than one year; more than 5 years; etc.)
- **How many and what type of doctors were consulted** before starting the treatment? (i.e. family doctor; orthopaedic; neuro-surgeon; internist; neurologist; rheumatologist; psychiatrist; diabetologist; pulmonologist; etc.)
- How many **working days were lost** in a year because of chronic pain? (i.e. less than 10 days; from 11 to 30 days; from 31 to 60 days; more than 60 days, etc.)

¹⁹ In relation to this, *Stichting Pijn-Hoop* adds that "instead of this (i.e. the fact that they are not able to supply testimonies due to privacy reasons) in 1992 and in 2002 the Foundation wrote a paper about the situation of chronic pain and chronic pain patients in The Netherlands. These papers are based on information collected by interviewing on the phone, during meetings and trainings people suffering from chronic pain and they provide a view about the general problems related to chronic pain in The Netherlands in these last years. These papers provide also recommendations and suggestions for improvement. All these problems still exist and are unsolved as of 2013. In order to provide information about experiences *Stichting Pain-Hoop* has organized training courses for people able to give interviews, train or explain pain. These services are also provided in English as are the papers".

- Before seeing a specialist/specialized centre for the treatment of chronic pain, did he/she try **alternative medicine** for chronic pain relief? (i.e. chiropractic; homeopathy; homotoxicology; naturopathy; osteopathy, acupuncture, prana, etc.)
- How the patient lives his/her **daily life** with **chronic pain**:
 - **Ordinary activities**: chronic pain causes more... (give examples such as chronic fatigue and insomnia; loss of appetite; impact on the ability to concentrate, reflect and remember; impact on the relationship between a couple, family and interpersonal effects on sexual life; impact on employment; impact on social activities and leisure, etc.)
 - **Psychological functions**: chronic pain causes more ... (i.e. mood swings; anxiety; depression, loss of self-esteem, insecurity, suicidal thoughts, etc.)
 - **Fears**: chronic pain causes more ... (i.e. fear of pain; fear of losing dignity; fear of prolonged hospitalization; fear of side effects of the treatment; fear about the family; uncertainty about the future, etc.)
 - **Social status**: chronic pain causes more... (i.e. loss of social status, loss of prestige at work and earnings; loss of the role in the family, sense of abandonment, etc.)

7.3 Life goes on, even with pain, 7 days a week, 24 hours a day

We have tried to stress only one aspect in each testimony. It would be enough though to read the first of the following stories to understand the situation in which many people in Europe and in the world live. But each testimony collected by patients' associations and civic organizations deserves special attention since each of them has a specific reason due to personal experience, objective difficulties, the dignity with which chronic pain is faced and, despite the situation, the great inner strength to go on and not give in.

Chronic pain & Volunteering

V. is a Belgian patient suffering from chronic pain and a volunteer at an association of patients.

"It's not easy and it takes time before you can start filling up days again with things that are meaningful to you. How long exactly this takes depends on the individual, every situation is different.

I know now by experience that there will always be bad days, and depression is never far away. That's nothing to be ashamed of, but you have to learn to fight these feelings. It's important to find out for yourself what you can still do despite the pain. It's not always bad to push your boundaries, but you should remain on safe ground. I myself have a tendency of crossing my own limits, mainly because I live alone and it's hard to pass on work to someone else.

One of the most difficult aspects of living with chronic pain is losing your job and, by consequence, ending up in an impasse. You feel useless and guilty for living at society's expense. That's why volunteering at the Vlaamse Pijnliga means so much to me. Of course, it's not the same as a real job, but it gives you a purpose and you can help others.

This also gave me the opportunity to get to know new people, people with chronic pain or another chronic illness. They usually understand you better than your own entourage. Because this is where things often go wrong. Since you're constantly confronted with pain, you feel the need to talk about it, but most of your friends and family members can't handle this. They immediately shift the conversation to something else, or simply ignore what you say. That really hurts, although most people don't mean it that way.

A lot of friends give up on you. At first they still invite you, but after you've had to say no because of the pain a couple of times, they stop bothering. Then when you have a better day and people see you walking on the street, they say "well, it appears she's healthy enough to take a walk, but not to work...". That hurts, even after 10 times, even after 100 times.

What people can't see is the condition you're in at home, how you need to rest after every effort you make, how many pills you have to take to get there. The worst thing is that you can't see pain from the outside.

Apart from the emotional problems, there's the financial aspect. Being set back to incapacity benefit is anything but a laugh. Medication and medical treatment is expensive, even in a prosperous country like

Belgium. You have to start using your savings, every month. That is, if you've had the luck of being able to put some money aside before you got sick.

What I miss very much are the hobbies I used to have. I was a very active person, both in my job and in sports. Now I can't do either of those any more. That's another way I lost a lot of friends. I used to have quite a number of friends living abroad, but I can't travel there anymore, because of the pain and because of the cost. I can't invite people over to stay at my place anymore either. I had to move to a smaller apartment so there's not enough room for that.

What helps me get through the days is my dog. Her friendship is unconditional, to her pain doesn't matter. Unfortunately, I must say, unlike many people and unlike society today. But still I know I'm not alone in this. And that's what keeps me going too: being able to talk with other people, pain patients and others, about pain and the problems it causes, that really helps".

Chronic pain & disability

From Austria we collected the very special testimony of Christine S., 58 years old, a woman struggling with pain for over 40 years. Among other things, what emerges is the need to recognise chronic pain in order to have the right to a disability pension.

"The problem with me started 44 years ago when in one month I suddenly grew 10 centimetres from 1.73 m to 1.83m. As a result I could hardly sit, walk or stand - I was even too weak to eat. My GP then prescribed pain killers and nutritional supplements; however, in spite of this, health complaints quickly showed: inflammation of the Achilles tendon on both sides.

Orthopaedist N° 1 then ordered soothing ointments and shots as a therapy and forbade any kind of sport, including gym for the next four years. With this problem solved, tendonitis started in both hands, which at times made it necessary to have the hand put into a cast, sometimes both of them. After my first year in a job the problem soon took over the whole spine, the muscular system and all tendons. Therapy: injections and pain killers.

Orthopaedist N°2 at that time said to me: "My good girl, if at forty years of age you will still be able to walk and sit and stand erect this indeed would be extraordinary'. The years that followed were marked by endless cycles of shots, physiotherapy and drug medication.

In the 1980s, when no therapy showed a lasting effect, Orthopaedist N°3 diagnosed "Fibromyalgia" for the first time. He based this on the nature of my pains: they appeared again and again as suddenly as they went. Sometimes on the right side of the body, then the left, then all over for days on end. The simplest tasks would not only tire me but leave me utterly exhausted. At the same time I became extremely sensitive to light, cold, smells and drafts. Unfortunately, no adequate therapies were known at that time and I could no longer take medication since my stomach and intestines had already begun to suffer.

My "use" of doctors so far: 3 Orthopaedists, 1 Neurologist (infusions and speech therapy), 3 Rheumatologists (one of them diagnosed "hypermobility of joints" but did not offer a therapy), 1 Pain specialist (acupuncture), 1 Specialist in complementary medicine (homeopathy) and 1 physiotherapist (cranio-sacral). Thus, I could stay in my job and care for my parents at the same time.

Eventually, however, **the pains got worse so that in 2002 I had to apply for disability pension which has been denied again and again because they could not acknowledge "fibromyalgia" as a disease in its own right.** Some official experts figured my symptoms to be some sort of pneumonia; others attributed the cause for them to the stomach or the thyroid. I was classified as "self-pitying", "not wanting to work", "feigning pain attacks" and describing symptoms previously learnt by heart.

The pains I suffer limit my possibilities of maintaining social relationships. For instance, I sometimes have to cancel appointments/engagements at short notice or break them off at an early stage. Because I have learnt to surround myself only with people who know my condition and fully accept it; I have no psychological problems. I have also learnt to avoid stress in my daily life. What cannot be done right away will have to wait until a later date. I am also not looking into the future. It is more important to live for the moment and indulge in small pleasures such as a beautiful sunrise or sunset.

In 2008 I heard that there are multimodal therapies available now, combining exercise, medication, psychotherapy, complimentary medicine, Physio- and Ergotherapy as well as patient education. I also found out that untreated hypermobility could result in fibromyalgia.

In the end I learnt to deal with my condition by observing the following facts: don't allow people to label you a psychic case, listen to your body, chose your doctors and therapists according to their real (and not feigned) knowledge of fibromyalgia, remain critical to offers in the internet which promise relief of your pain and finally exchange ideas with fellow sufferers”.

Response to pain according to age

These are interesting testimonies from Bulgaria and are a comparison between the different reactions of two men, a 30 year old and a 74 year old; the first is employed while the second is retired.

The older patient is 74 and retired. After the first signs of pain, he waited 4-5 years, because, he says “*I accepted pain as a part of life*”.

Before starting the treatment of his disease, he consulted a GP and a neurologist, then “for half a year” he was in treatment for chronic pain management.

Before that, he tried homeopathy as alternative medicine for chronic pain relief. In a year, he lost “about 30” working days because of chronic pain.

In ordinary activities, chronic pain has a detrimental impact on interpersonal relationships, families and couples are often affected negatively. These impacts may extend to negative impacts that couples experience in their sexual life.

Psychologically, it causes loss of self-esteem, insecurity and fear of pain; socially, the loss of the role in the family.

The second testimony is that of the younger patient: 30 years old, married, civil servant. Contrary to the older patient, after the first manifestations of pain, he waited only “several months” to go to the doctor since he had been self medicating “with pain-killers”.

As well as a GP and a neurologist, he consulted also a neuro-surgeon, then “for two years” he was in treatment for chronic pain management. Before that, he also tried homeopathy and acupuncture.

In one year, he lost “more than 50 working days” because of chronic pain.

However, he does not wish to comment on how chronic pain affects his daily life he and what chronic pain causes more...

Chronic pain & lack of trust in physicians

From Finland comes the testimony of a woman, 45 years old, “married, logistics engineer, retired”.

She decided on self medication, probably she did not have a good enough relationship or trust with doctors: “*after 3 months I went to see my GP. It was waste of time as he wanted to treat my stomach instead of my back. I underestimated the problem, I thought it is an ‘age’ problem and I took care of myself with painkillers*”.

She has been in treatment for 14 years: “I use a neurostimulator” but she has not consulted any other doctor.

“*I fear that someday the medication will not work any longer. There are not so many medicines which I haven’t already tried already*”.

In ordinary activities, “*everything is more difficult than it used to be. I’m not able to walk long distances, I can’t lift anything, I cannot do normal domestic work, I just look at the days go by*”.

Regarding psychological functions, she has “sometimes problems in sleeping”, and as far as social status is concerned, “*we do not visit people as much as we use to. Instead they visit us. I have lost prestige and earnings at work, the money I bring home is almost nothing*”.

Chronic pain & workers' rights

From Macedonia we have the testimony of a man, 54 years old, married, pump attendant which makes us reflect on the need for greater protection of people suffering from chronic pain and that this is an issue that should also be of interest to the trade unions.

He waited 1 week to visit a doctor for a back pain with probable spinal disc herniation. He couldn't visit a doctor due to work obligations. He had these problems for 7 years. He visited an orthopaedic doctor, his GP and a radiologist. He had about a total of 30 days of sick leave in the last year. He tried to go to a rehabilitation centre with chiropractic sessions, exercises and electric stimulations. In his daily activities **the main problem is his job because he is always standing and he cannot sit.** He goes to his GP for injections and goes to work after that. **His supervisor doesn't give him sick leave and that is making the problem worse.** He has sleeping problems and during the day he is nervous. His mood is altered. He thinks that he needs to change his job but it is not possible at the moment. He feels helpless.

Chronic pain & access to new therapies

The need to facilitate access to new drugs and therapies. Here is a significant testimony of a woman from Macedonia, 49 years old, with rheumatoid arthritis, married with 3 children. She is a teacher and she has suffered from pain in the palm joints and small joints on her feet for the past 3 years. The pain is intense in the morning. She has visited her GP, a rheumatologist and an orthopaedic clinic. She waited 1 year to visit a doctor. She has been on treatment for 2 years. She has lost about 1 week work due to sick leave. She hasn't tried any alternative medicine. **She struggles to get new biological modern therapy which she has read about on the internet in the new guidelines for rheumatoid arthritis, but this cure is not available for free in her country and it is too expensive for her to buy it herself.** She receives traditional therapy which has several side effects. The disease is making her life difficult because of the pain, especially in all activities carried out in the morning. She is scared of the progression of the disease and of the side effects of the medicines.

Chronic pain: money problems and waiting lists

The patients' association from Malta has supplied the following testimony (a common experience that can be taken as a scenario experienced by many).

Mrs B. is a 65 year old female, retired, worked for most of her life as a housewife but when her children married and left home she started working as a cleaner in a residential home.

When she turned 60 she started suffering from joint pains which resulted in advanced osteoarthritis, this was managed using various medication until a couple of years ago she needed a knee replacement. In the meantime she lost her husband and has become totally dependent on her 2 married daughters who have their own family. **She has been on a waiting list for a knee replacement for the past 2 years** and in the meantime she has lost a lot of her independence, she had to leave her job which gave her security and stability together with some extra cash so that now her only income is her pension. **Ms B. cannot afford to resort to private intervention, she never had a health insurance which could cover the expense, but out of her pockets she does not have close to €7500 to have the surgery done.** She still receives her free recommended medicine to relieve her of her pain but in the meantime she is suffering in all areas – socially, emotionally and physically, until she can have the knee replacement on the national health scheme. Her only hope is that her health will not deteriorate further making her too frail to face the much awaited operation. Hope is the last to die and like many other people Mrs B. is hopeful to have her knee replacement done soon and be able to enjoy a better life.

Luckily Mrs B. needs only a knee replacement: had she needed a hip-replacement the cost would be higher by at least another €1000.

Chronic pain & social misconceptions

We chose a witness from the Netherlands to represent a patient who lives with chronic pain and experiences social difficulties.

*"Chronic pain totally changes your life. It forces you to say goodbye to your previous way of living. This hurts and it takes time to get accustomed to the changes. Sometimes you can lose your job and your social contacts and **there is a lot of misunderstanding because others can't always see the pain.** Also under a financial point of view chronic pain is a nasty illness. Often there is a need of self- remedies for which there is no reimbursement. For example, the cost of ready prepared meals. You find yourself unable to do the*

dishwashing (machines are very expensive). There are a lot of examples for which life with chronic pain is expensive.

It is possible to build a better life, but you have to search daily and try to strike the right balance between what you are willing to do and what you can do".

When doctors do not believe the patient

Slovenia, the testimony of a woman who denounces the attitude of doctors, who are not inclined to believe and to listen to her for as long as it is necessary.

"It took several years for doctors to believe me. I live in constant pain. They treated me as a hypochondriac. Therefore, I wasn't getting my condition properly managed at the earliest stage and I was denied access to therapies for pain management. I was getting very little information regarding my condition, mainly because the doctors didn't know exactly what was wrong with me. Doctors also didn't take enough time to talk to me properly. I feel I was denied a right to be informed about all the pain management options available so I could not make the best decisions for my condition. I feel I was denied my right to live with the least amount of pain possible".

Female, 40 years old, married, mother of two children, a gardener by profession. I have coped with the disease for 12 years now. At first I felt the pain in the arms and shoulders and neck, later in the legs and then throughout the body. I was constantly very tired and without energy, so I became less efficient both at home and at work. Because of my problems I have been at the disability commission. In my everyday life I face a lack of understanding in my workplace. I was acknowledged the right of working only part-time, but my performance at work is worsening. People see me as "someone who is constantly complaining." *"Thank God for my (patient) organization, family and friends for all they do to cheer me up. I try to alleviate my pain through exercises, swimming and pain therapy. The worst thing is that I can't fully devote my attention to my family. I tried all sorts of alternative treatment options, all with little success. Despite the fact I'm working only part-time I'm on sick leave a lot. I currently have a problem with constant headaches and undertake acupuncture sessions in hospital in Brežice. The disease, whose progress scares me, makes me think that one day I will become completely incapable of functioning at work or at home, so I live in constant fear".*

Underestimated of pain

Slovenian female, 38 years old, married, recording clerk at court. "I waited to seek professional help about my pain for over six years since I first started to feel the pain. I delayed it for so long because I underestimated it. For each pain in a specific part of my body I had found an explanation (hands hurt, because I previously worked in catering and I was in contact with cold water a lot, shoulders and neck would hurt due to excessive sitting at work, feet hurt, because I'm too heavy, I have back pain because I'm not working out, headaches because of the computer work). I have been in treatment since July 2012 (9 months). In 2012, I was often on sick leave, from 30 to 60 days all in one go, and I often used my vacation time for it. I have not tried alternative treatment yet.

The impact of pain on my life: even the smallest tasks are causing me problems, I'm constantly unbearably tired. Even for everyday tasks I have to ask my children (age 10 and 6) to help me. I keep forgetting names, faces, daily responsibilities, at work I have problems remembering what I did, until I check the file. I am very absent-minded, because I get so easily disturbed even by a radio playing or someone talking next to me. Because of my forgetfulness I'm constantly looking for something. I feel the dreams that I've had for the future have been shattered. I have difficulties coping with my work, where I have a very responsible position. I'm constantly worried I'll make a mistake. My children have no mother to play with. I spend most of my free time sleeping, because I'm always endlessly tired. I'm not seeing any of my friends anymore and I prefer to stay at home. Many times I am very nervous because I have to ask for help for doing the smallest thing. I'm sick with the mess at home, which I can no longer take care of. I often feel useless and see myself in the eyes of others as someone who is merely pretending. If these people could only know how much I would like to be able to work like everyone else! I'm scared that I will not be able to function - not only at

work but also at home. I'm afraid that when this really happens I will not be able to secure enough money to live a decent life and give my children a proper education".

Over 120 days lost because of pain

Slovenia, the case of a young man forced to take many days of rest, the situation doubly painful because of the many lost working days and the inability to continue to have an active lifestyle and to do sports.

"I am single, 30 years old, a senior clerk in the court by profession. My problems started over a year ago, but I waited for over three months before I was diagnosed with fibromyalgia. The medical treatment started nine months ago. Because of the pain I was on sick leave for over 120 days last year. Prior to treatment by a specialist I tried an alternative method of pain relief with little success. Because of the pain I have problems with insomnia, which in turn makes me more tired than usual. I have problems concentrating and with memory more and more often. I do not spend my free time as I did in the past (various sports and other activities). All my free time is reserved for rest after work. Also, I do not socialise as I used to and I do not engage in social activities because of pain, for I have problems sitting or standing for long time. I experience frequent mood swings, which hinder me at work as well as with normal everyday activities. I have got used to my pain and I am not afraid of it, but I fear my social position will gradually deteriorate. I'm deeply grateful to my family, friends and colleagues who understand me and that makes my life a lot easier".

Many doctors and many alternative medicines demonstrates an attitude not to give in

Willing to live and the determination not to give in to pain are expressed through consulting many doctors and using many alternative medicines.

This is the testimony that comes to us from a UK woman, 57 years old, married. She is unable to work and therefore retired due to ill health.

She waited one year before deciding to consult a physician. **Her GP felt that referring the patient to the hospital was not necessary**, so she wrote to a medical director of the hospital. **There was a 9 month waiting list.**

She has been in treatment for 12 years.

During this time, she consulted many doctors (GP, a Gynaecologist, a Gastroenterologist, Pain Specialists, a Radiologist and a Physiotherapist) **and tried "everything" in alternative medicine** for chronic pain relief: acupuncture, homeopathy, herbal medicine, reflexology, EMDR²⁰, hypnotherapy.

Related to the effects of chronic pain, she states a *"significant reduction in income, leisure and social activities, difficulty travelling, inability to sit without extreme pain, standing and walking also painful. What further complicated her life is that she is sensitive to the side effects of medication. At doses where she does not experience significant side effects she also does not have therapeutic relief of her pain."*

The risks of self-medication

Spain: 48 years old woman, married, administrative assistant.

It took her a little over a year to go to a doctor. The Primary Care Centre took 1 year to send her to a specialist. Probably this was attributed to her personal situation she was going through - the illness of a close relative - so she would medicate herself with pain killers since she was working in the health sector.

She has been in treatment for the last 10 years and she has consulted only a family doctor and a rheumatologist.

In daily activities, chronic pain causes her *"chronic fatigue and insomnia, lack of concentration and memory, difficulty to think, difficulties at work, in social activities and leisure"*. Related to her social status, chronic pain has caused her to feel a "loss of good standing at work".

Chronic pain & lack of information

Testimony of a retired woman from Spain which clearly shows us how much the lack of information can be dangerous.

²⁰ Eye Movement Desensitization and Reprocessing (EMDR), developed to improve coping and reduce chronic pain and suffering.

She is 65 years old and married. After the first signs of pain she waited "more than ten years" before deciding to consult a specialist for the treatment of chronic pain. The reason? ***"Because of the lack of information about the illness and also because the family doctor would not diagnose it".***

She has been in treatment for chronic pain for 12 years, and before retiring she was off sick about 10 days a month throughout her whole professional life.

She didn't try any alternative medicine for chronic pain relief, but she consulted lots of different doctors: one primary care doctor, an ear, nose and throat specialist, a gynaecologist all in Switzerland, three primary care doctors, a urologist, a family doctor and an ophthalmologist all in La Coruña.

Currently, she shows signs of fear, panic attacks, anxiety, mood changes, disorientation, continuous sadness, insomnia and hypersensitivity.

In care for 17 years but with a great will to live better

From Sweden we have received the following positive example: she is a 56 years old woman, married and on a disability pension. After the first signs of pain, she waited "approximately one year" before deciding to consult a specialist for the treatment of chronic pain. As she said, "I was waiting for the pain to disappear".

She has been on treatment for chronic pain management for 17 years.

She has tried many types of alternative treatments for chronic pain relief: reflexology, chiropractic, naturopathy, acupuncture, and consulted two doctors.

During her daily ordinary activities, chronic pain results in poor sleep, bad memory and tiredness: "I try to not let it affect my social life. I try to have an active one, and choose to take the consequences of my choice (more pain and more fatigue).

Regarding psychological functions: *"No nothing like that. After my diagnosis I decided to make the best of the situation, and try to live my life as normal as possible. And the only fear I have is the possible side effects from medical treatment".*

Regarding her social status, she says *"only economic loss. Not anything else"*.

Chronic pain & sex life

In the testimony of a Swedish lady of 54, married, on sick leave (applying for sickness compensation); we refer to the consequences that chronic pain causes in the sexual sphere of a person. She waited "approximately ten years" before consulting a doctor, *"since the pain was moving around I thought I had different problems in my body that came and disappeared back and forth. I didn't think it was caused by ONE problem. But after my mother was diagnosed with fibromyalgia, and I noticed that we shared several symptoms, I went to see a doctor because I suspected that I might be suffering from fibromyalgia too"*.

She doesn't take any *"treatment at the moment, except vitamin B12 and folic acid for my fatigue. I have often been offered medical treatments, but I have always declined. For some time I have taken paracetamol, but it didn't help much. For some years I underwent hydrotherapy in warm water (34°), and have also been to physiotherapy sessions a few times. Also tactile massage therapy a few times, but that treatment is not subsidized by the state so it's too expensive to do on a regular basis"*.

During the years, she has consulted "several doctors at several health clinics, but I never received any help. Then I went to a rheumatologist, but I didn't get any help there either. Then to a private pain centre, and there – at last – I was diagnosed in 2004 (17 years after my pain started, in 1987) fibromyalgia.

*"It affects my ordinary life. Sleeping problems make me wake up several times every night, which prevents me from getting a beneficial sleep, and I don't feel refreshed when I wake up in the morning. My pain results in comfort eating, which makes me gain weight, and this makes me feel worse. Impairment regarding concentration and memory - definitely. I can ask about something that I already asked 5 minutes earlier, and it happens often. Both my husband and I live with pain, and also our daughter, and of course this can create irritation when you are not feeling well and when you are tired. But at the same time we have an understanding and we try to help each other in any way we can. **Of course pain affects sexual life, so you have to try to come up with your own tricks to be able to have some kind of sex life.** To a certain extent I avoid certain social activities. For example I don't go to the cinema because loud volume bothers me; I'd rather*

stay at home and watch a film on TV. I try to attend social activities, but my condition sometimes forces me to leave early. I love travelling, and I try to do it despite the pain, uncomfortable beds, etc., since I get a positive feeling from seeing new places, and meeting new people.

Regarding mood swings, I tend to be easily irritated. I'm not particularly depressed, I have accepted my disease. I want to live, and I want to do and experience things. I fear possible side effects from medical treatments, and that's why I say no to them. I feel you have to pay more than you gain. I'm not afraid of the pain, I know that some things create more pain, but I don't avoid everything for that reason. Both my husband and I are sick, so we are in the same boat. I don't feel that I have lost anything regarding social status. Regarding work prestige I have "exchanged" work for my engagement in a patient organization. Of course I have experienced an economic loss, which is inevitable. You just have to adjust to that. But I don't feel less valuable than healthy people just because I'm not able to work anymore. I used to work, and pay taxes too".

Chronic pain & depression

Austrian Susanne F., 62 years old, tells us the sad story of her chronic pain and the operations she has had that have caused a state of depression from which derive her most fearful thoughts. "For the past 30 years I have been living in pain attributed to the cervical spondylosis. In 1991 a disk prolapsed of the fifth and sixth vertebrae and required surgery, which led to a second operation in 2000, stabilizing C4 - C6 with a plate. It took 14 years until therapy eventually was started. Up to then I consulted 4 General Practitioners, 3 Orthopaedists, 4 Neurologists, 4 Physiotherapists, 2 Psychologists and various outpatient clinics.

Therapies tried: physiotherapy, TENS, various electrical current treatments, moor packs, massages (underwater, acupuncture, foot reflexology, lymphatic drainage), craniosacral therapy, bio-feedback, acupuncture, autogenic training, Jacobson relaxation, homeopathy, Grinberg method, Feldenkrais bodywork, tai chi, counselling by psychologists. Several weeks in hospital at least once a year.

Since 1997 twice weekly treatment at a Pain therapist (epidural injections, nerve root blockades, infiltrations, medication according to the grade scheme of the WHO: opiates, anti-depressants, anti-inflammatory drugs, most treatments and doctor consultations are not paid by the National Health Service but have to be paid by the patient.

My life until 1983: an interesting job rich in variety, sport activities (tennis, aerobics, swimming), fitness training 3 times a week, weight training, many friends, skiing and vacations, cinema, theatre, restaurant visits etc.

After 1983: pain in the cervical area of the neck, which was treated only with alternative methods and physiotherapy. However, the pain increased, spreading via the left arm down to the fingertips. This was diagnosed in 1986 with tendonitis and meant wearing a cast for 10 days. More pain which made me consult an orthopaedist (infiltrations and physiotherapy twice a week). Hospitalization at least once a year. In spite of all treatments no reduction of pain, not even a reliable diagnosis.

1990: intolerable pain led to the first CT which showed a prolapse of the 5th and 6th disk.

1991: surgery, after symptoms of paralysis appeared in my left arm. However, after the surgery I suffered severe shoulder pain which was diagnosed as radiating pain, a few years later as a complete rotator cuff tear.

Since 1997 I have been treated by an anaesthetist twice a week and received for the first time a medication that helped (opiates). This made it possible for me to go on with my job although I was never without pain. Depression followed and more stays in hospitals. In 2000 more surgery was necessary, this time disks from 4 to 6 were plated. Still had so much pain that I was forced to reduce my working hours and eventually had to retire at the age of 55.

Living with extreme pain is sometimes intolerable and limiting. I have to carefully plan visits to the cinema or meeting friends, which anyway is only possible on "good days". Bigger events, such as attending a concert, are only possible after treatment by my pain therapist. Impromptu undertakings depend on how much pain I feel and are therefore very rare. A so-called normal life is impossible. This excludes activity holidays; long car drives are not possible anymore as is participating in sports. On the other hand vacation in a warm climate is highly appreciated, since I have become very sensitive to cold. **There is hardly anything left from my old activities which leads me to experience depression, mainly attributed to the fact that there is nothing**

positive to expect from the future. Due to the problems with the cervical area of the neck I am suffering sudden dizzy spells, causing blackouts which in turn lead to falls. Broken ankles, broken metatarsal one, broken shoulder, rupture of the rotator cuff.

In addition I am suffering from gammopathy, angina pectoris, heartburn, gastritis, anterior spinal artery syndrome, allodynia, coxarthrosis, osteoporosis and depression.

Suicide? For me a possible solution if nothing helps anymore”.

The importance of civic organizations for the protection of rights

From Italy, the significant testimony of Mrs. Lucia who thanks a civic association for the work it is doing in informing patients, but then complains that the NHS does no longer provide certain type of services. The shortcomings of the Italian NHS affect also patients suffering from chronic pain.

“Dear Cittadinanzattiva,

I wish to thank you for the guide ‘In-Dolore’ published by your organisation since it has made me aware of my health care rights.

These problems affect my daily life since I’m suffering from chronic pain and I know what it feels like to be told ‘you’re pains are compatible with your age’ as if I should resign myself to feeling old at 56.

*Therefore, the National Health provides certain types of treatment such as TENS²¹ and, after 15 days, according to their point of view, you might even go mountain climbing. Now I would like to know how come that after a course of acupuncture at the Hospital in Sesto San Giovanni in Milan, with fantastic results, the treatment was no longer provided not even at Ospedale Bassini where, however, the benefits were not the same. This treatment **was discontinued without giving any future hope to the patients**. Please note that this treatment was provided by the National Health Scheme.*

I also wish to give my testimony about palliative care.

I applied for this type of service for my father, at the hospital in Sesto San Giovanni, and ‘incredibly’ for the first time he was listened to and given the best attention. Through this service we have been able to give him a dignified death.

Yours sincerely”.

We wanted to conclude this chapter with this very special letter of thanks. It is a small but sincere acknowledgement of our good work that is extended also to so many associations and organizations devoted to the protection of rights and to the support of people who are suffering.

²¹ The TENS (Transcutaneous Electrical Nerve Stimulator) is a tool that produces electric shocks used to stimulate the nerves through the skin. The TENS are used in the treatment of pain.

CHAPTER 8 – SYNTHESIS OF DATA AND CONCLUSIONS

8.1 Summary

The relevance and timeliness of the information obtained through the present civic survey is reflected in the statement by the *Foundation Pijn Platform Nederland* "since 2012 there is an ongoing survey in The Netherlands. This survey has two purposes: 1. to develop a C Q-index (wishes, demands, and expectations): a tool to measure quality of help for pain patients and 2. a questionnaire made by patients to assess the factors for a good treatment of (chronic) pain. All aspects in the above issue are part of this survey. The final report and the implementation plan are expected to be completed by 2013/beginning of 2014".

As already described in the chapter on the methodology the starting point of the present civic survey was the listing of five evaluation factors:

1. The patient's right to be believed.
2. The patient's right to have pain treated and managed at the earliest possible stage.
3. The patient's right of access to the best possible technologies and therapies in pain treatment and management.
4. The patient's right to be informed about all the pain management options available so that he/she can make the best decisions and choices for his/her wellbeing.
5. The patient's right to live with the least amount of pain possible.

With a positive and constructive approach, it is now the case to emphasize the positive aspects and those of excellence in order to improve the culture of the fight against pain in the various European countries.

8.1.1. Positive aspects at institutional level

At institutional level the survey, even if expressly addressed to the Ministry in charge, collected useful information to reflect on the entire working of national institutions.

From this point of view based on the information collected it appears that the commitment of the institutions in the fight against unnecessary pain, based on the above mentioned five main evaluation factors, seems to be as follows:

- Austria is sufficient regarding only factor 2, in particular thanks to the easy access to care, at least from the economic point of view;
- Belgium is sufficient only regarding factor 5, thanks in particular to the economic benefits granted as well as to the assignment of specific functions within the Ministry in the field of pain;
- Bulgaria is sufficient both as regards factor 1, because of the fairly widespread practice of the measurement of pain, and factor 2, for the same reason registered in Austria;
- Italy is excellent regarding factor 1 (the periodic measurement of pain is required by law); good regarding factor 2 (thanks to the requirements for an easier access to medicines for patients suffering from chronic pain); sufficient regarding factor 4 (through information campaigns and web), excellent regarding factor 5 (fully complies with the requirements, i.e. ad hoc national regulations, an office of reference at ministerial level, an information system available to the Ministry to monitor the phenomenon, the presence - albeit partial - of social-economic benefits for the patients);
- Macedonia is insufficient regarding all factors;
- Malta is sufficient with regard to three factors of evaluation (1, 2 and 5), for measuring pain, for accessibility both to drugs and to care, and for the fight against unnecessary pain thanks to a data collection service and a specific ministerial office;

- Portugal is sufficient regarding factors 1 and 2 (thanks to the guidelines on the measurement of pain and the facility for patients to access medication and treatment; factor 5 is excellent thanks to a specific legislation relating to pain prevention, social-economic benefits, the presence of data collection services and a specific ministerial office which allows the Ministry to be updated and thus constantly monitor the situation;
- Slovenia is excellent regarding factor 1 (legislation on measurement of pain) and sufficient regarding factor 5 (in addition to the existence of specific national legislation there is a data collection system available to the Ministry and - even if only partially – there are social-economic benefits for those suffering from chronic pain);
- Sweden is excellent regarding factor 1 (measurement of pain); good regarding factor 2 (cost of care and lack of excessive restrictions on access to medication to help those who suffer from chronic pain), excellent regarding factor 5 (there is a data collection system available to the Ministry and there are ample social-economic benefits).

On the issue of the fight against pain, there is a law in Italy which is considered in the forefront, and although Italian institutions do more the Swedish ones do it best.

This in synthesis is the situation from the point of view of the contribution given by the Ministries responsible for the respect of the right of patients not to suffer.

8.1.2. Positive aspects at civic level

Which is the point of view of the patients? If Malta, as mentioned in Chapter 5, stands unrivalled in the first place in each of the five evaluation factors, what is the situation in the other countries? Here follows a brief summary:

- Spain, Slovenia, Romania and The Netherlands show an unsatisfactory performance in all 5 of the assessment factors.
- UK and Latvia are unsatisfactory in 4 out of 5 assessment factors and are sufficient only as regards factor 3 due to the lack of legislation and/or protocols which prohibit physicians from prescribing the most adequate chronic pain treatment.
- Italy and Finland show a sufficient assessment only regarding factor 4, mainly because, fortunately, there are no cases of chronic pain patients who overuse/abuse drugs for chronic pain treatment.
- Sweden is unsatisfactory in 3 out of 5 evaluation factors and sufficient only in factor 1 (measurement of chronic pain is guaranteed in both cases of hospitalisation for non-surgical reason and for post-surgical chronic pain) and regarding factor 2 (mainly because the rate of economic difficulties of chronic pain patients in accessing treatment is low).
- Cyprus is satisfactory regarding factor 3 (there is neither legislation nor protocol which prohibit physicians to prescribe the most adequate chronic pain treatment for chronic pain patients) and regarding factor 5 (as a whole, the violation of the patient's right to live with the least amount of pain possible does not seem very common in the structures under survey).
- Germany and Belgium show a sufficient performance regarding three evaluation factors:
 - factor 2: in both countries in very rare cases chronic patients are denied proper treatment for chronic pain when it is deemed necessary from their point of view.
 - factor 4: German patients very seldom find it difficult to understand medical language; Belgian pain patients have no difficulty in accessing existing services for chronic pain treatment at local level and doctors provide information about alternative care.
 - factor 5, in both countries there are no cases in which physicians have refused to prescribe the adequate medication, and rarely chronic pain patients are excluded from social and/or financial support because of their economic situation.

- Except regarding factor 2, Bulgaria is sufficient on factor 1 (mainly in measuring post and non post-surgery pain) and is good regarding the other three factors, in particular:
 - factor 3, there are no restrictive laws or protocols that prohibit physicians from prescribing the most adequate chronic pain treatment for chronic pain patients.
 - factor 4, there is a good level of information as well as the absence of reports indicating difficulties in understanding the physician and of cases of abuse of drugs.
 - factor 5, there are no problems in Bulgaria regarding waiting lists for diagnoses, opiates being refused and lack of communication between GPs and specialised doctors.
- Austria does not show any structural shortcomings in any of the evaluation factors: on the contrary, it achieves top marks on factor 3 (absence of legislation or protocols prohibiting physicians from prescribing the most adequate chronic pain treatment for chronic pain patients). Evaluation regarding the remaining factors is sufficient in all cases. In particular:
 - factor 1, the measurement of pain and the involvement of chronic pain patients' associations in the development of chronic pain management for chronic pain patients and/or families is a widespread practice.
 - factor 2, there are no known cases of violation of patient's right to have pain treated and managed at the earliest possible stage.
 - factor 4, information obtained by patients as regards explanation of the treatment and on the use of alternative cures is adequate.
 - factor 5, there are no known cases of physicians having refused to prescribe adequate medication.
- Portugal does not show any structural shortcomings in any of the five evaluation factors. In particular:
 - factor 1, sufficient (measurement of pain is widespread practice); factor 5, sufficient (physicians do not refuse to prescribe adequate medication).
 - factor 2, good (there are no known cases of patients with economic problems having difficulties in accessing their chronic pain treatment); factor 4, good (as in the case of Austria patients receive adequate information on the treatment they are undergoing and on alternative cures).
 - The evaluation reaches top marks for factor 3 due to the absence of legislation and/or protocols that prohibit physicians from prescribing the most adequate chronic pain treatment for chronic pain patients (as already mentioned, this situation is also common to other countries).

8.2 Ministries versus civic patients' associations

The following table shows a synthetic evaluation both at institutional and civic level using the data made available by the 9 countries involved in the research.

Tab.8.1 - The Right to avoid unnecessary suffering and pain from two points of view

Civic patient association		The Right to avoid unnecessary suffering and pain		Ministry of Health	
EVALUATION	SCORE	COUNTRY	SCORE	EVALUATION	
ALMOST RESPECTED	72	AUSTRIA	19	NOT RESPECTED	
NOT RESPECTED	45	BELGIUM	22	NOT RESPECTED	
PARTLY RESPECTED	69	BULGARIA	24	NOT RESPECTED	
NOT RESPECTED	33	ITALY	77	ALMOST RESPECTED	
NOT RESPECTED	33	MACEDONIA	10	NOT RESPECTED	
FULLY RESPECTED	98	MALTA	31	NOT RESPECTED	

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ALMOST RESPECTED	76	PORTUGAL	51	HARDLY RESPECTED
NOT RESPECTED	27	SLOVENIA	38	NOT RESPECTED
NOT RESPECTED	30	SWEDEN	92	FULLY RESPECTED

The comparison between civic patients' associations and Ministries shows the following three trends:

■ **Full compliance** in the overall assessment by both the Ministries of Health and associations. This is the case of Belgium, the Republic of Macedonia and Slovenia, where evidently the shortcomings are clear and known to all. If nothing else, there is uniformity in assessing the situation for what it is, which is an indispensable prerequisite. It is essentially also the situation in Portugal where evaluations are characterized by subtle but basically convergent differences.

■ **An anomalous situation** in the case of Austria and Malta where the institutional point of view is stricter than that of the Associations. Less pronounced but all the same evident this situation is also found in Bulgaria. Excess of optimism? Need for further and more thorough investigation? Few expectations or a "line of credit" granted by civic associations to the local political class? We cannot exclude any of these hypotheses; certainly the third point of view, the one of the professionals, will undoubtedly help to have a better idea.

■ **Totally opposite evaluations** instead emerge in Italy and Sweden as regards the institutional point of view compared to the Civic one for the following three reasons:

- diversity among the associations
- knowledge of the context: peculiarities of each country and common economic difficulties
- high expectations by civic organizations

8.2.1 Diversity among associations

A first general consideration is the fact that the **associations involved are diverse**, which could presumably lead them to pay greater attention to some aspects and less to others. As shown in the Appendix, there are for example associations of patients suffering from arthritis and rheumatism (Malta), from diabetes (Latvian), from myeloma (Romania), from fibromyalgia (Slovenia and Sweden), from *Síndrome de Fatiga Crónica y Sensibilidad Química Múltiple* (Spain), and others suffering from Machado-Joseph disease (Portugal)²². Moreover, also umbrella organizations (such as in the UK) and pools of associations which do not constitute a real network have participated in the civic survey having considered the importance of joining forces (as in the case of Bulgaria and the Netherlands), but not neglecting to emphasize their different points of view, as clearly shown in the reports.

Finally, there are also civil society organizations such as the European Social Forum Cyprus and Cittadinanzattiva which are not patients' organizations but promote civic participation which in the case of the Italian movement, include also the protection of rights. It is therefore no coincidence that the colleagues who collected the data have accompanied them by the following premise: "Please note that Cittadinanzattiva is not a patient organization, therefore the information gathered refers to complaints from citizens (related to violations of rights in health care).

²² We consider particularly useful to recall the peculiarities of the disease the patients in the Portuguese "Associação de Apoio ao Atlântica doente Machado-Joseph" suffer from. Machado-Joseph disease (JDM) is a hereditary neurological (autosomal dominant transmission), chronic and highly disabling disease. The main area of the brain affected is the cerebellum (responsible for motor coordination). The main symptoms are: a) lack of coordination of movement; b) imbalance; c) swallowing difficulties; d) speech difficulties ("dysarthria"); e) "double" (diplopia) and "misty" vision; f) protruding eyes (due to eyelid retraction); g) spasticity (stiffness of the limbs); h) muscle atrophy.

Obviously the diversity among associations was taken into account at the time the research was prepared, convinced as we are that the different points of view represented an added value rather than a problem. The same way as certain phenomena are observed through different lenses.

These associations are very active in their field. For example, in the UK "the *Pelvic Pain Support Network* has recently implemented an NHS Right Care multi-disciplinary population based workshop in London with the aim of reorganizing services for those with chronic pelvic pain at national level. A follow up workshop is planned in Southampton with the intention of piloting and evaluating the outcomes of such an approach. This would enable services to be accessible to patients at regional level".

In Bulgaria, the Patients' Organization *Together with You* states that "our organization holds meetings among groups of chronic pain patients and psychologists to share problems and provide psychological assistance. We work actively to improve access to chronic pain medical products which are reimbursed by the NHIF and to enlarge the list of drugs paid by public resources. We organize regular information campaigns to inform patients about their right to avoid pain and their right to be believed".

The Arthritis and Rheumatism Association of Malta "in with collaboration with the Health Promotion Department is working on an initiative to organise courses in self management. Preparations are still undergoing to fully develop the training courses and obtain necessary funding. The training targets various chronic conditions and not only musculoskeletal diseases".

The Fibromyalgie en Samenleving association F.E.S from The Netherlands points out that "a correct step will be offering the possibility of treatment. Due to lack of offer of a correct treatment after diagnosis, the Fibromyalgie en Samenleving F.E.S developed the training path "don't struggle alone" in which patients can tell their story and have the possibility to come up with solutions. This is a self-management training course in 6 meetings. The reactions were very positive. Patients learnt to come up with solutions and not only focus on their complaints. Also the feedback from professionals involved was very positive. This association has a long history in the quest for right treatments. It is with satisfaction that we see patients who afterwards take part in multidisciplinary programmes.

The latest activities carried out by Cittadinanattiva in Italy regarding fight against pain are:

- the association conveys the patients' comments in its yearly report on Law no. 38/10 of the Italian Ministry of Health to the Parliament.
- Empowerment campaign for citizens regarding Law no. 38/10: pediatric and chronic pain, how to speak to one's GP and how to access existing health services.
- Promotion of the "Mario Luzi" award on pain.
- Promote citizens' presence in the "Ospedale territorio senza dolore" committees.

8.2.2 Knowledge of the context: peculiarities of each country and common economic difficulties

One should always take into account the **different situations in the 17 countries involved, their starting points and the present economic difficulties which do not allow the Ministries to allocate substantial resources.**

The different contexts prompt the authorities to prioritise certain aspects at the expense of others. Therefore, after certain rights have been guaranteed, often after years of struggle by civic organizations, the lack of others may be looked at with a certain amount of leniency.

Let us take for example the case of Romania, where the *Myeloma Euronet Romania* association explains the situation in the country: "with the exception of the specialized clinics for the treatment of pain and private clinics, in Romania, we do not have a good system at the level of the national ministry of health for the management of pain. This is partly due to the lack of funds; the Ministry of Health continues to receive under 5% of the GDP, as well as the lack of specialized medical staff for the treatment of pain. Note: So far, 28,890 medical doctors left Romania, 7500 in 2010, and most of them are presently working in Western European clinics. Due to this social-economic problem and the low income of the population (the average monthly salary being somewhere around Euro 300), there are very few patients who make use of private clinics or specialized centres for the treatment of pain, which are also private. In most cases,

patients go to state clinics and state hospitals for their pain problems. The time allocated by the doctors usually does not take longer than 30 minutes maximum per patient (used for both filling in the medical report and medical consultation) and in most of the cases they are addressing the acute phase of the pain rather than its chronic aspect. Regarding information, this is very seldom given to the patients (in state owned establishments) and when it comes to prescribing medication it is even worse because of the shortage of drugs, including cytostatics on the market. As a result even if the patients are clearly eligible for reimbursement by the National Health House, due to this medication shortage they end up in self-procurement from the private pharmacies and self-payment".

A similar scenario is also depicted by the Latvian *Diabetes Association*, which states: "in recent years, attention has been paid to chronic pain issues, and special centres have been established both in the state-funded healthcare centres, multiprofile hospitals and in private healthcare institutions. The positive fact is that specialists in those centres help choose a modern and effective analgesic therapy (both pharmacological and non-pharmacological) in a rational way, taking into account all the patient's diseases and risks, as well as his/her financial resources. The negative fact is that the lack of funding for the healthcare system by the State leads to a situation in which patients must treat diseases with oral medicines instead of surgery. In these cases, also the specialists in the pain management centres become the victims of insufficient funding; therefore the help they provide cannot be effective.

The most acute problem in Latvia is insufficient funding for scheduled surgery, as well as the fact that only a very restricted number of such surgeries are funded, therefore becoming practically unavailable. In a state with a great number of low-income citizens, patients are not in the position to pay for surgery. This explains why they suffer from long term pain and lose the capacity to work until their turn comes or when their health problem becomes so acute that state-funded medical help can be obtained. For instance, this concerns hip arthroplasty, other arthroplasties, hand surgeries, gall bladder surgeries, gastric ulcer, talipes (club foot). This is the reason why a greater number of Latvian people suffer from pain compared with those in developed countries. Due to insufficient funding, the state reimbursed drugs are not prescribed to all patients in need (for instance, diabetes mellitus patients with painful diabetic neuropathy cannot always obtain state reimbursed even if this is the most appropriate product".

On the other hand, being aware of the situation, the associations in some cases may have high expectations and this is discussed in the following paragraph.

8.2.3. High expectations

A third consideration no doubt arises from the high expectations by civic organizations especially where the institutional framework, given by legislation, consolidated and good practices, structures, etc... might lead to expect much more than what is before their eyes on a daily basis.

Evidently, this is the case of Italy: it is not sufficient to have a well advanced law (l.38/2010) if there are difficulties in its application at regional level (since some Regions have yet to issue the appropriate regulations). This is due to a series of factors such as the lack of a culture on fight against pain among the public administrators, a lack of training for health operators (mainly GPs), a use of specific drugs which in Italy is the lowest in Europe and little knowledge of the issue among citizens (although 12 million Italians suffer from pain).

The example of Sweden, despite the established practice of measuring pain may not be a sufficient argument when there are cases in which doctors do not spend enough time to listen to chronic pain patients on the one hand, and, on the other, little or nothing is done to form associations to represent and protect them.

In short, who relies on high expectations has a careful and critical take on the role of the institutions, since this should be combined with a constructive and unprejudiced approach which allows the promotion of an effective governance approach. This is therefore how the fight against unnecessary pain at Community

level, should be dealt with involving all relevant stakeholders like patients, civic associations, health care providers and professionals, the scientific community and also industry and other institutions.

8.3 Professionals, it's your turn!

Obviously, the work presented in this survey could be integrated and improved upon and therefore all suggestions will be most welcome. Some have already been forwarded by associations such as the *Fibromyalgie en Samenleving F.E.S.* from The Netherlands which observes that "what is missing in the questionnaire is the contact with the general practitioner who is generally in contact with the patient. The attitude of the general practitioner can make a lot of difference in dealing with chronic pain".

We think that one of the most important factors is the integration of the collected data with those supplied by the professionals which would help us to obtain a comprehensive picture of the overall situation. Therefore, on the basis of these premises, we are committed to prepare a second edition of the present survey to be presented in the second half of 2013.

8.4 Objective: the Italian EU Presidency in the 2nd half of 2014

Currently, the following actions are particularly important in the reform of Health policies: reinforcing alliance-building between organizations and groups, enlarging participation in the assessment procedures; producing civic information for policy input; being proactive and not only reactive citizens; building partnerships with all the stakeholders in the Health sector (professionals, local institutions, companies, universities, etc.); and, last but not least, sharing with and learning from each other.

This report wishes to be a contribution towards to better understand which concrete proposals against pain we want to propose to European Institutions, to National and local government, to physicians and professionals. For this reason, the subjects involved in this research are invited to work together to identify the answers in terms of "pathways" in order to remove the violations and to disseminate the existing good practices.

In the second part of 2013, several stakeholders will be involved in debates with patients' associations about the pathways to be promoted to reduce pain, obstacles, difficulties, cultural and social barriers in a patients' forum.

We hope that the final result of this work will be a list of all the actions to put patients with pain at the centre of Health policies. This list of pathways and actions will have as a priority patients' concerns, which can be different from medical or organizational concerns. The stakeholders involved - including governmental representatives - will play a supporting role as experts in identifying the best solutions.

The final goal is to formulate these "Pain Patient Pathway Recommendations" put forward by the citizens' associations and submit them to the vote of the European institutions during the Italian EU Presidency in the 2nd half of 2014.

Why Italy and the Italian European semester? Because Italy has one of the best legislations protecting this type of pain, Law no.38, therefore the Italian institution could be more favourable and would fight together with the patients' associations to have this issue included in the EU agenda.

Law no. 38/2010 puts Italy in the forefront on the children's palliative care and in the treatment of pain, so much so that the UN has suggested adopting the Italian law as a "model" law for a global legislation adopted by all UN member countries. This is a long journey towards a great objective: making in Europe pain relief a right for all chronic patients beginning with children.

ATTACHMENT 1 : FACTORS OF EVALUATION, SUB FACTORS AND INDICATORS

The patient's right to be believed

Level 1: Ministry of Health

MEASURING PAIN: Is there a national/regional requirement (state law or ministerial acts such as protocols/recommendations, etc...) which requires the measurement, the evaluation and the annotation of patients' pain at regular intervals?

	Yes, in all cases	Yes, but only in some cases*	Never	N/A
At hospitals:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At private clinics:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In pain-specialised centres:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At retirement homes:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In home care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
First Aid Emergency Room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

* For instance, patients with particular conditions or illnesses, or in certain wards.

Level 2: Civic organizations/patient's associations

PHYSICIANS' CONSULTATION: Does your chronic pain patient association have knowledge of chronic pain patients reporting that their GP (family doctor) did not spend enough time to listen to their complaints regarding chronic pain?

Yes ☐ No ☐ N/A ☐

If yes, state how often: Often ☐ Sometimes ☐ Rarely ☐

PATIENT EMPOWERMENT: Is your chronic pain patient association involved in the development of chronic pain management for chronic pain patients and/or families?

Yes ☐ No ☐ N/A ☐

If yes, state where and how often:

	Often	Sometimes	Rarely	Never	N/A
At hospitals:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At private clinics:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In pain-specialised centres:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At retirement homes:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In home care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
First Aid Emergency Room:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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POST-SURGICAL PAIN: Does your chronic pain patient association have knowledge of lack of measurement of post-surgical chronic pain?

Yes ☐ No ☐ N/A ☐

If yes, state where and how often:

	Often	Sometimes	Rarely	Never	N/A
At hospitals:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At private clinics:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MEASURING PAIN: Does your chronic pain patient association have knowledge of non-measurement of chronic pain in cases of hospitalisation for non-surgical reasons?

Yes ☐ No ☐ N/A ☐

If yes, state where and how often:

	Often	Sometimes	Rarely	Never	N/A
At hospitals:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At private clinics:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In pain-specialised centres :	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At retirement homes:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In home care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
First Aid Emergency Room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

VIOLATION OF THE PATIENT'S RIGHTS: Does your chronic pain patient association have knowledge of cases in which the patient's right to be believed according to your interpretation is violated?

Yes ☐ No ☐ N/A ☐

If yes, state where and how often:

	Often	Sometimes	Rarely	Never	N/A
At hospitals:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At private clinics:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In pain-specialised centres :	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At retirement homes:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In home care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
First Aid Emergency Room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

The patient's right to have pain treated and managed at the earliest possible stage

Level 1: Ministry of Health

COST OF TREATMENT: What system is used by the National Health Service to prescribe medication and medical services listed below to chronic pain patients for the treatment of chronic pain?

	Totally free for citizens	Totally paid by citizens	Co-payment*	Prescription Charges**	N/A
Drugs:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical devices:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical specialist:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical rehabilitation:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospitalisation:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Surgery:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological support:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical home:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home nursing:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travel for treatment in home country:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travel for treatment abroad:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

* Economic integration: the patient pays part of the costs of drugs.

** Fixed fee: the patient contributes to the costs of the National Health Service.

RESTRICTIVE LAWS: In the last year has the government carried out a study to determine whether the existing national/regional laws are overly restrictive with regard to the control and use of drugs within the National Health System to the point of hindering the prescription, distribution or access to medical treatment or drugs for chronic pain patients?

- ☐ Yes
☐ No, because this study has previously been done
☐ No
☐ N/A

TO FACILITATE ACCESS TO DRUGS: If so, have any necessary changes been made to facilitate access to drugs by doctors and chronic pain patients?

	Yes	No	N/A
According to law:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
According to official guidelines, protocols for pain management, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

Level 2: Civic organizations/patients' associations

PAINKILLERS/MORPHINE NOT ADMINISTERED: Does your chronic pain patient association have knowledge of chronic patients being denied proper chronic pain treatment when it seems necessary according to the view of the chronic pain patient/family?

Yes ☐ No ☐ N/A ☐

If yes, state how often: Often ☐ Sometimes ☐ Rarely ☐

ECONOMIC DIFFICULTIES: Does your chronic pain patient association have knowledge of chronic pain patients having economic difficulties in accessing their chronic pain treatment?

Yes ☐ No ☐ N/A ☐

If yes, state how often: Often ☐ Sometimes ☐ Rarely ☐

	Often	Sometimes	Rarely	Never	N/A
When paying for drugs:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When paying for medical devices:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When paying for a medical specialist:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When paying for medical rehabilitation:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When paying for hospitalisation:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When paying for home care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When paying for psychological support:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When paying for home nursing:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When paying for travel for treatment in home country:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When paying for paying travel for treatment abroad:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

VIOLATION OF THE PATIENT'S RIGHTS: Does your chronic pain patient association have knowledge of cases in which the patient's right to access to prompt management of his/her chronic pain, according to your interpretation, is violated?

Yes ☐ No ☐ N/A ☐

If yes, state where and how often:

	Often	Sometimes	Rarely	Never	N/A
At hospitals:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At private clinics:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In pain-specialised centres :	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At retirement homes:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In home care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
First Aid Emergency Room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

The patient's right of access to the best possible technologies and therapies in pain treatment and management

Level 1: Ministry of Health

PROFESSIONAL UPDATING/TRAINING: in the last year, has the Government/Ministry of Health invested any funds in professional updating/ training/ educational initiatives aimed at professionals in pain treatment and management? If so, this was for:

Medical Professional	Yes	No	N/A
Specialized doctors in the treatment of pain, for example in palliative care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialized doctors in the treatment of pain, for example experts in pain management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapists / Rehabilitators	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social assistants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Geriatricians	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oncologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatricians	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiotherapists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

TRAINING FOR CHRONIC PAIN PATIENTS' ASSOCIATIONS: in the last year, has the Government/Ministry of Health funded training initiatives aimed with chronic pain patient associations?

Yes ☐ No ☐ N/A ☐

Level 2: Civic organizations/patients' associations

RESTRICTIVE LAWS: Does your chronic pain patients' association have knowledge of legislation and/or protocols that prohibit physicians from prescribing the most adequate chronic pain treatment for chronic pain patients?

Yes ☐ No ☐ N/A ☐

VIOLATION OF THE PATIENT'S RIGHTS: Does your chronic pain patients' association have knowledge of cases in which the patient's right to have access to the best possible technologies and therapies in chronic pain treatment and management, according to your interpretation, is violated?

Yes ☐ No ☐ N/A ☐

If yes, state where and how often:

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

	Often	Sometimes	Rarely	Never	N/A
At hospitals:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At private clinics:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In pain-specialised centres :	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At retirement homes:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In home care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
First Aid Emergency Room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The patient's right to be informed about all the pain management options available so that he/she can make the best decisions and choices for his/her wellbeing

Level 1: Ministry of Health

COMMUNICATION CAMPAIGN: In the last year, has the Government/Ministry of Health promoted and financed at least one communication campaign for chronic pain patients/citizens on the specific issue of non-cancer related chronic pain (to affirm the right not to suffer unnecessarily, to make known pain centres, new legislation, treatment options and therapies, risks from drug abuse, etc.)?

Yes ☐

No ☐

☐ N/A

INVOLVEMENT OF CHRONIC PAIN PATIENTS' ASSOCIATIONS: if so, has the communication campaign directly involved chronic pain patients' associations engaged in the issue of chronic pain and the protection of patients' rights?

Yes ☐

No ☐

☐ N/A

WEBSITE: In the last year, has the Government/Ministry of Health set up a website dedicated to the issues of chronic pain, so that chronic pain patients and citizens can easily find information and organisations to turn to?

Yes ☐

No ☐

☐ N/A

Level 2: Civic organizations/patients' associations

LOCAL SERVICES: Does your chronic pain patients' association have knowledge of cases in which the chronic pain patient complained about the difficulty in locating existing services at local level for chronic pain treatment?

Yes ☐ No ☐ N/A ☐

If yes, state how often: Often ☐ Sometimes ☐ Rarely ☐

DIFFICULTY IN UNDERSTANDING MEDICAL LANGUAGE: Does your chronic pain patients' association have knowledge of cases in which the chronic pain patient complained because his/her doctor, in prescribing and explaining the therapy (i.e. pharmacology, physiotherapy, etc.) used terminology that was too technical or difficult to understand?

Yes ☐ No ☐ N/A ☐

If yes, state how often: Often ☐ Sometimes ☐ Rarely ☐

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

LACK OF INFORMATION: Does your chronic pain patients' association have knowledge that the treating physician did not explain the treatment properly?

Yes ☐ No ☐ N/A ☐

If yes, state what information was left out and how often this occurred:

	Often	Sometimes	Rarely	Never	N/A
What are the procedures for a proper use of medication:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How to self-manage therapy:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Duration of treatment:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Contraindications:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Side effects:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risk of addiction:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Type of prescribed drugs (opiates, non-opiates):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any changes recommended to patient's behaviour/posture/lifestyle:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Proper diet to follow:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any changes recommended in sleeping habits:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ALTERNATIVE CARE: Does your chronic pain patients' association have knowledge of cases in which the chronic pain patient complained because when talking about treatments and therapies, the doctor did not inform him/her about any alternative care:

Yes ☐ No ☐ N/A ☐

If yes, state what kind of therapy and how often:

Complementary therapy	Often	Sometimes	Rarely	Never	N/A
Chiropractic:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Homeopathy:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Naturopathy:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Osteopathy:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acupuncture:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapy:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alternative therapy	Often	Sometimes	Rarely	Never	N/A
Iridology:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reflexology (feet reflex therapy):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hypnotherapy (mesmerist):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

OVERUSE/ABUSE OF DRUGS: Does your chronic pain patients' association have knowledge of cases of chronic pain patients who overuse/abuse drugs for chronic pain treatment?

Yes ☐ No ☐ N/A ☐

If yes, state how often: Often ☐ Sometimes ☐ Rarely ☐

VIOLATION OF THE PATIENT'S RIGHTS: Does your chronic pain patient association have knowledge of cases in which the patient's right to be informed, according to your interpretation, is violated?

Yes ☐ No ☐ N/A ☐

If yes, state where and how often:

	Often	Sometimes	Rarely	Never	N/A
At hospitals:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At private clinics:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In pain-specialised centres :	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At retirement homes:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In home care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
First Aid Emergency Room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

The patient's right to live with the least amount of pain possible

Level 1: Ministry of Health

NATIONAL LAW: Is there a national law concerning the management of chronic pain?

Yes ☐ No ☐ ☐ N/A

UPDATE: Is there a central information system to collect data on performance of the drugs dispensed in the treatment of chronic pain?

Yes ☐ No ☐ ☐ N/A

If so, does it concern:

	Yes	No	N/A
Hospitals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Private clinics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain-specialised centres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Retirement homes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
First Aid Emergency Room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPOINTED OFFICIAL: within the Government/Ministry of Health, is there an official/representative appointed to deal with issues related to chronic pain and the fight against unnecessary pain?

Yes ☐ No ☐ ☐ N/A

SOCIO-ECONOMIC BENEFITS: Is there a provision at national/regional level (state law or only ministerial acts/recommendations, etc.) ensuring the right to socio-economic benefits to people suffering from chronic pain, such as:

Financial support	Yes	No	N/A
Cash benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Absence from paid work/sick leave payment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recognition of a degree of disability/disability pension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social support	Yes	No	N/A
Wheelchairs, chairs, special beds and so on	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

Level 2: Civic organizations/patients' associations

WAITING FOR THE DIAGNOSIS: Does your chronic pain patients' association have knowledge of cases in which chronic pain patients who approached Health Services waited for too long before having their chronic pain status diagnosed?

Yes ☐ No ☐ N/A ☐

If yes, state how often: Often ☐ Sometimes ☐ Rarely ☐

REFUSAL TO PRESCRIBE OPIATES: Does your chronic pain patients' association have knowledge of physicians who have refused to prescribe adequate medication?

Yes ☐ No ☐ N/A ☐

If yes state which medication was refused and how often:

Medication	Often	Sometimes	Rarely	Never	N/A
Opiates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-opiates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

LACK OF COMMUNICATION: Does your chronic pain patients' association have knowledge of cases in which a chronic pain patient complained about the lack of communication between the family doctor and the specialized doctor, about the course of treatment?

Yes ☐ No ☐ N/A ☐

If yes, state how often: Often ☐ Sometimes ☐ Rarely ☐

SOCIO-ECONOMIC BENEFITS: Does your chronic pain patients' association have knowledge of cases where chronic pain patients are excluded from social and/or economical support because of their economic condition?

Yes ☐ No ☐ N/A ☐

If yes state what kind of support and how often it was denied:

Financial support	Often	Sometimes	Rarely	Never	N/A
Cash benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Absence from paid work/ sick leave payment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recognition of a degree of disability/ disability pension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social support	Often	Sometimes	Rarely	Never	N/A
Wheelchairs, chairs, special beds and so on	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Civic Survey on Patient's Rights for the Respect of Unnecessary Pain in Europe

VIOLATION OF THE PATIENT'S RIGHTS: Does your chronic pain patients' association have knowledge of cases in which the patient's right to avoid pain, according to your interpretation, is violated?

Yes ☐ No ☐ N/A ☐

If yes, state where and how often:

	Often	Sometimes	Rarely	Never	N/A
At hospitals:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At private clinics:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In pain-specialised centres :	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At retirement homes:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In home care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
First Aid Emergency Room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please note:

As shown in the methodology (see relevant chapter), the value assigned to each answer (from 0 to 100) expresses the degree to which the information gathered meets with the legitimate expectations of the citizens. In particular:

- The value used for each indicator in the questionnaire for the Ministry of Health (level 1) is:
 - 100 – 0 for questions with only 2 options
 - 100 – 50 – 0 for questions with 3 options (with the exception of the indicator “Restrictive laws” where the value is 100 – 75 – 0).
- The value used for each indicator in the questionnaire for civic organizations/patient's associations (level 2) is: 100 – 70 – 40 – 0.

ATTACHMENT 2: LIST OF PARTICIPANTS IN DATA COLLECTION AND ACKNOWLEDGMENTS²³

Publication

This section shows in alphabetical order for each country the list of all chronic patients' associations and civic organisations involved in the civic survey with all relevant details (website, email, logo when possible), contact person, ministry officials, various stakeholders and partners who have made possible the collection of all the information.

In particular, name, position and email address of the people who have filled in the questionnaire addressed to the patients' associations and to the Ministry of Health.

Our thanks goes to all who have contributed to the research and in particular to those associations which, although less equipped, have put in the best effort in order to meet the requirements of the civic survey as shown by the following testimony which we have purposely reported anonymously: "as a nonprofit organization, our possibilities are limited and we rely on volunteer workers as well as the cooperation of health care professionals and political contacts". Thank you so very much!

AUSTRIA:

Civic Partner involved in the project

Organization name: EURAG Austria (EURAG Österreich)

e-mail: eurag@eurag.at

Website: www.eurag.at

Contact person: Erika Folkes

The questionnaire addressed to the patient association was filled in by:

The questionnaire to the Associations was drawn up with an expert from HOPE

Organization name: LKH-Bruck-Mur

Name and Surname: Elisabeth Sackl-Pietsch

Position: Dr. Med., MBA, MPA

e-mail: elisabeth.sackl-pietsch@lkh-bru.at

The questionnaire addressed to the Ministry of Health was filled in by:

The Austrian Official Patient Representative (Arge Patientenanwälte) instead of Ministry of Health

Name and Surname: Dr. Gerald Bachinger

Position: Speaker of 9 Austrian Patient Representatives

e-mail: gerald.bachinger@noel.gv.at



BELGIUM:

Civic Partner involved in the project

Organization name: Vlaamse Pijnliga

e-mail: vlaamsepijnliga@cm.be

website: www.vlaamsepijnliga.be

Contact person: Pieter Herwege

The questionnaire addressed to the patient association was filled in by:

Organization name: Vlaamse Pijnliga

Name and Surname: Pieter Herwege

The questionnaire addressed to the Ministry of Health was filled in by:

Name and Surname: Christiaan Decoster

Position: Director-General at DG for Healthcare facilities organization, Federal Public Service (FPS) Health, Food Chain Safety and Environment - Ministry of Social Affairs and Public Health

e-mail: christiaan.decoster@gezondheid.belgie.be



²³ By Daniela Quaggia, Project Manager Active Citizenship Network.

BULGARIA:

Civic Partner involved in the project

Organization name: Index Foundation

e-mail: indexfoundation@mail.bg

website: www.index-bg.org

Contact person: Ludmila Mincheva

The questionnaire addressed to the patient association was filled in by:

Organizations name: 'Together with You'; Association for Reproductive Health, Pregnancy and Childcare 'Smile'; Alliance of Transplanted and Operated; 'Future for Everyone' Association of Patients with Cardiovascular Diseases.

Name and Surname: Penka Georgieva

Position: Chairperson Together with You

email: pgeorgieva@dir.bg

The questionnaire addressed to the Ministry of Health was filled in by:

Name and Surname: Dr. Elvira Foteva

Position: Chief Expert Directorate - Medical activities and electronic healthcare

e-mail: efoteva@mh.government.bg



CYPRUS:

Civic Partner involved in the project

Organization name: EUROPEAN SOCIAL FORUM CYPRUS (ESFC)

e-mail: chrysis@esfc.org.cy

website: www.esfcypus.eu

Contact person: Chrysis Michaelides

The questionnaire addressed to the patient association was filled in by:

Organization name: EUROPEAN SOCIAL FORUM CYPRUS (ESFC)

Name and Surname: Chrysis Michaelides



FINLAND:

Civic Partner involved in the project

Organization name: Suomen Kipu ry - Finnish Pain Association

e-mail: liisa.mikkonen@suomenkipu.fi

website: www.suomenkipu.fi

Contact person: Liisa Mikkonen

The questionnaire addressed to the patient association was filled in by:

Organization name: Suomen Kipu ry - Finnish Pain Association

Name and Surname: Liisa Mikkonen



GERMANY:

Civic Partner involved in the project

Organization name: Deutsche Schmerzliga e.V. (German Pain League)

e-mail: info@schmerzliga.de

website: www.schmerzliga.de

Contact person: Harry Kletzko

The questionnaire addressed to the patient association was filled in by:

Organization name: Deutsche Schmerzliga e.V. (German Pain League)

Name and Surname: Harry Kletzko

Deutsche Schmerzliga e.V.



ITALY:

Civic Partner involved in the project

Organization name: Cittadinanzattiva- Active Citizenship Network

e-mail: m.votta@cittadinanzattiva.it

website: www.cittadinanzattiva.it www.activecitizenship.net

Contact person: Mariano Votta

The questionnaire addressed to the Ministry of Health was filled in by:

Name and Surname: Marco Spizzichino

Position: Director XI Office

e-mail: m.spizzichino@sanita.it

The questionnaire addressed to the patient association was filled in by:

Organization name: Cittadinanzattiva- Active Citizenship Network

Name and Surname: Valeria Fava, Sabrina Nardi

e-mail: v.fava@cittadinanzattiva.it s.nardi@cittadinanzattiva.it



LATVIA:

Civic Partner involved in the project

Organization name: Pacientu Ombuds - Patients' Ombud Office

e-mail: ombuds@pacientuombuds.lv

website: www.pacientuombuds.lv

Contact person: Liene Sulce-Revele

The questionnaire addressed to the patient association was filled in by:

Organization name: Latvian Diabetes Association

Name and Surname: Gunta Freimane

Position: Chairperson of the Board

e-mail: domubiedri@gmail.com



Pacientu Ombuds

MACEDONIA:

Civic Partner involved in the project

Organization name: Medicine and Ecology Research Centre - MERC

e-mail: merc.ngo@gmail.com

website: www.merc.mk

Contact person: Darko Iliev

The questionnaire addressed to the patient association was filled in by:

Organization name: NORA

Name and Surname: Lazo Efremov

Position: President

e-mail: lazo.efremov@gmail.com; office@nora.mk

The questionnaire addressed to the Ministry of Health was filled in by:

Name and Surname: Dr Zoran Stojanovski

Position: Head of the Department for Primary Health Care

e-mail: zsapg@t-home.mk



MALTA:

Civic Partner involved in the project

Organization name: Malta Health Network

e-mail: info@maltahealthnetwork.org

website: www.maltahealthnetwork.org

Contact person: Gertrude Buttigieg

The questionnaire addressed to the patient association was filled in by:

Organization name: Arthritis and Rheumatism Association Malta

Name and Surname: Mary Vella

Position: President

e-mail: mary_vella@hotmail.com

The questionnaire addressed to the Ministry of Health was filled in by:

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As mentioned in the introduction, this civic survey on the state of cure and attention to pain has raised the interest of many professionals and institutions.

As an example, I wish to point out the interest in cooperating by the Spanish Xunta de Galicia – Departamento Acceso a la Salud and by the Italian Coordinator of the Regional Committee for the fight against pain of the Emilia-Romagna Region.

At the same time, several professional figures also from countries not covered by the research (Czech Republic, Hungary, Kosovo, Poland, and Russia) have made themselves available to supply competences and information.

My thanks go also to them for their support and constructive approach which is a positive example of cooperation among institutions, professionals and citizens which should never fail to happen in particular where people's health and dignity are concerned.

Back cover

About Pain Alliance Europe (PAE)

PAE is an NGO umbrella organisation of 23 national associations in 13 EU Member States, representing 275,000 individual patients committed to improve the quality of life of people suffering from chronic pain. For PAE, quality of life for a chronic pain patient means giving the patient the right to choose the best possible solutions and support to live his life according to his possibilities and wishes. PAE was officially founded in the European Parliament hosted by Marian Harkin (MEP, IRE) on November 29th 2011. It aims to promote awareness for chronic pain, to promote a European policy on chronic pain and to reduce the impact of chronic pain on the European society on all areas. More information: www.pae-eu.eu

About Active Citizenship Network (ACN)

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

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

About Grünenthal

The Grünenthal Group is an independent, family-owned international research based pharmaceutical company headquartered in Aachen, Germany. Building on its unique position in pain, its objective is to become the most patient-centric company to be a leader in therapy innovation. Grünenthal is one of the last five research-oriented pharmaceutical corporations with headquarters based in Germany which sustainably invests in research and development. These investments amounted to about 25 % of revenues in 2011. Grünenthal's research and development strategy concentrates on select fields of therapy and state-of-the-art technologies. We focus on the intensive search for new ways to treat pain better, more effectively and with fewer side-effects than before. Altogether, the Grünenthal Group has affiliates in 26 countries worldwide. Grünenthal products are sold in more than 155 countries and approx. 4,500 employees are working for the Grünenthal Group worldwide. In 2011, Grünenthal reached estimated revenues of 947 Mio €. More information: www.grunenthal.com.

