



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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FOREWORD (I)

1. The issue of Pain in the Charter of Rights

The objective of the Charters of Rights on health care is the enunciation of a "set of rights" which define and clarify the more general right to health.

1.1 The European Charter of Patients' Rights, promulgated in 2002 in a European context, specifically including the *right to avoid unnecessary suffering and pain*. It is the result of a joint effort between Cittadinanzattiva-Tribunal for Patients' Rights and 15 civic organizations partners of Active Citizenship Network (ACN).

1.2 Other two Charters, drafted in a National context, focus solely on the issue of the fight against unnecessary pain:

Charter of Rights for people living with Chronic Pain, written by Chronic Pain Ireland and approved by the Governing Body of Chronic Pain Ireland on 2009.

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

FOREWORD (II)

2. The civic assessment of the Right to avoid unnecessary pain

- In 2011, ACN performed a Civic Assessment on the EU Charter of Patient's Rights
- The assessment involved 20 EU countries, 56 hospitals, 23 Ministries of Health and 70 civic organizations
- It shows that the right to avoid unnecessary suffering and pain is hardly respected.
- Regarding the 11th "Right to Avoid Unnecessary Suffering and Pain":
 - „...unacceptably low score“
 - „...this gap suggests that effective respect for this right is blocked by organizational behaviour and resistance that diminish the efficacy of available services and hospital initiatives.“



RIGHT	ASSESSMENT	PRES
7. TO RESPECT OF PATIENTS' TIME	NOT RESPECTED	41
5. TO FREE CHOICE	NOT RESPECTED	43
2. TO ACCESS - care	NOT RESPECTED	46
3. TO INFORMATION	HARDLY RESPECTED	54
15. TO ACTIVE CITIZENSHIP	HARDLY RESPECTED	54
11. TO AVOID UNNECESSARY SUFFERING AND PAIN	HARDLY RESPECTED	58
9. TO SAFETY	HARDLY RESPECTED	60
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4. TO CONSENT	PARTLY RESPECTED	64
14. TO COMPENSATION	PARTLY RESPECTED	64
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12. TO PERSONALIZED TREATMENT	ALMOST RESPECTED	74
1. TO PREVENTIVE MEASURES	ALMOST RESPECTED	75
6. TO PRIVACY AND CONFIDENTIALITY	ALMOST RESPECTED	84
2. TO ACCESS - physical	ALMOST RESPECTED	84
TOTALS – MEAN VALUES	PARTLY RESPECTED	62

These negative results send a precise signal to the civic world and to European institutions about the work still to be done: it is a difficult challenge which needs to be faced as a joint effort.

3. Patients' approach to the improvement of pain management

- Despite the efforts at regional, national & European level, the condition of patients affected by chronic pain is still serious.
- A strong patient-oriented policy against chronic pain is therefore required.
- A multi-year (2012-2014) and multi-stakeholder project with a collaborative approach: Patients – Citizens – Industry



The political framework of the project is designed by Pain Alliance Europe (PAE) representing chronic pain patients in Europe.



Active Citizenship Network (ACN) is responsible for the scientific design and contents.



The pharmaceutical company Grünenthal GmbH (GRT) is responsible for financial and non-financial support.

MAIN STEPS OF THE PROJECT

- ***Report on the Assessment of the EU Patient Right of Avoiding Unnecessary Suffering and Pain*** in two edition (May and October 2013).
- ***Develop EU Pain Patient Pathways Recommendations:*** the Civic survey is a necessary step to understand which concrete proposals against pain can be put forward to European, National and local Institutions in order to identify pathways/recommendations against pain according to the patient's point of view for a good health policy on chronic pain relief.
- ***Submit these Civic Recommendations to the vote of the European institutions during the Italian EU Presidency in the 2nd half of 2014.*** Law no. 38 is a good law: therefore, the Italian institutions together with the patients' associations could make a joint effort in trying to have this issue included in the EU agenda.

Geographical impact of the survey

The area of investigation of the civic survey is composed of the following **18 countries**: Austria, Belgium, Bulgaria, Cyprus, Finland, Germany, Italy, Latvia, Macedonia, Malta, The Netherlands, Portugal, Romania, Slovenia, Spain, Sweden, The Uk (+ France for the II° edition of the civic survey, in October 2013).

3 TYPES OF INFORMATION RELATED TO 3 LEVELS OF INVESTIGATION:

- The first type concerns the degree to which institutional bodies are issuing norms and promoting policies and actions against unnecessary pain. These actions show the level of attention for people living with Chronic Pain at a national level. Sources: **Ministry of Health**
- The second type of information reflects the knowledge civic partner organisations have. They may offer a wide range of information on health care system, 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 third type of information concerns the direct experience of key health professionals who daily manage the care-pathways of Chronic Pain patients. Sources: **the national representatives of the European Associations of Health professionals**

METHODOLOGY AND TECHNICAL INSTRUMENTS

- The methodology is inspired by the method of “civic information”, 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.
- This is a qualitative survey rather than a quantitative one.
- The survey has no statistical value but provides a picture of main critical areas in the field of non oncologic chronic pain through data collected with the following instruments:

Questionnaires:

- for the partner organizations;
- for professional key individuals;
- for the Ministry of Health.

Guidelines for in-depth interviews and a Grid for the Good Practices

5 “FACTORS OF EVALUATION”

The survey takes as a reference the following 5 “factors of evaluation” linked to rights & principles described in the 2 Charters written in Italy and in Ireland:

- **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 with 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.*

DATA COLLECTION

- Each factor was subdivided into **51 sub-factors** which could be identified and measured to ascertain their correspondence to the fundamental parameters necessary to evaluate the implementation level of each factor.
- Each sub-factor was “translated” in a group of indicators (in total, **174 indicators**) detectable through closed-ended questions. All questions refer to the last 12 months.
- A value was assigned to each type of expected answer. 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, 100 is given whenever it is verified to be the best situation.
- For a more “immediate” reading of the results, an **average score** was assigned to each factor, i.e. a numeric value indicating the distance from the top according to the result obtained: **0-40 = WEAK; 41-70 = SUFFICIENT; 71-90 = GOOD; 91-100 = EXCELLENT.**
- Each evaluation factor assesses the ability of each country to respect “the Right to avoid unnecessary suffering and pain” according to the following **rating: 0 – 50 = NOT RESPECTED; 51 – 60 = HARDLY RESPECTED; 61 – 70 = PARTLY RESPECTED; 71 – 90 = ALMOST RESPECTED; 91 – 100 = FULLY RESPECTED**

Synthetic Table of the Rights of people living with Chronic Pain

5 factors of evaluation	Organization level		Institutional level		Professional level		Total	
	<i>sub-factor</i>	<i>Indicator</i>	<i>sub-factor</i>	<i>Indicator</i>	<i>sub-factor</i>	<i>Indicator</i>	<i>sub-factor</i>	<i>Indicator</i>
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

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

The Right to avoid unnecessary suffering and pain	Right to be believed	Right to have pain treated at the earliest stage	Right of access to the best possible therapies	Right to be informed	Right to live with the least amount of pain possible	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

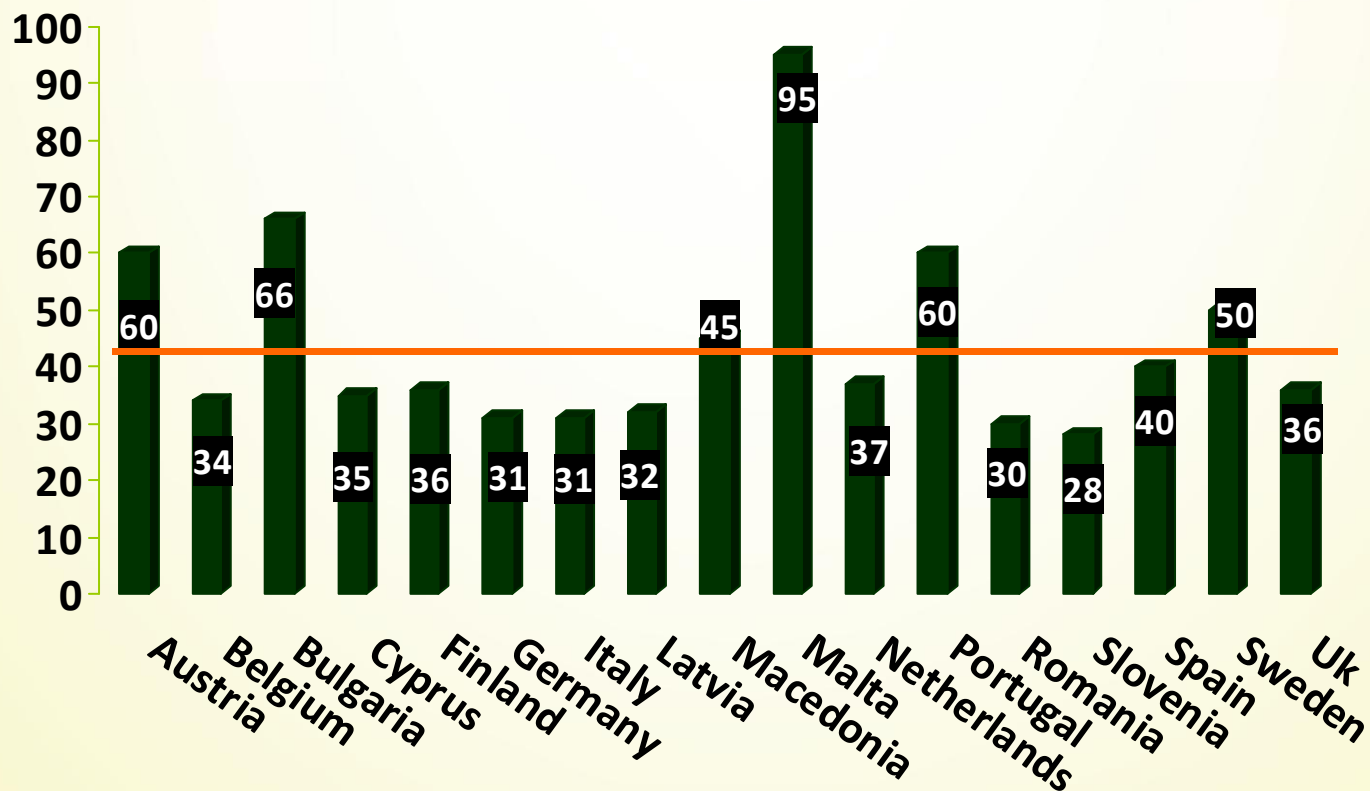
ACCORDING TO THE INFORMATION COLLECTED BY PATIENT/CIVIC ORGANIZATIONS:

- **At European level**, 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, Portugal.

- **At national level**, the Right to avoid unnecessary suffering and pain is not respected in 13 Countries, partly respected in Bulgaria, almost respected in Austria and Portugal, fully respected in Malta.

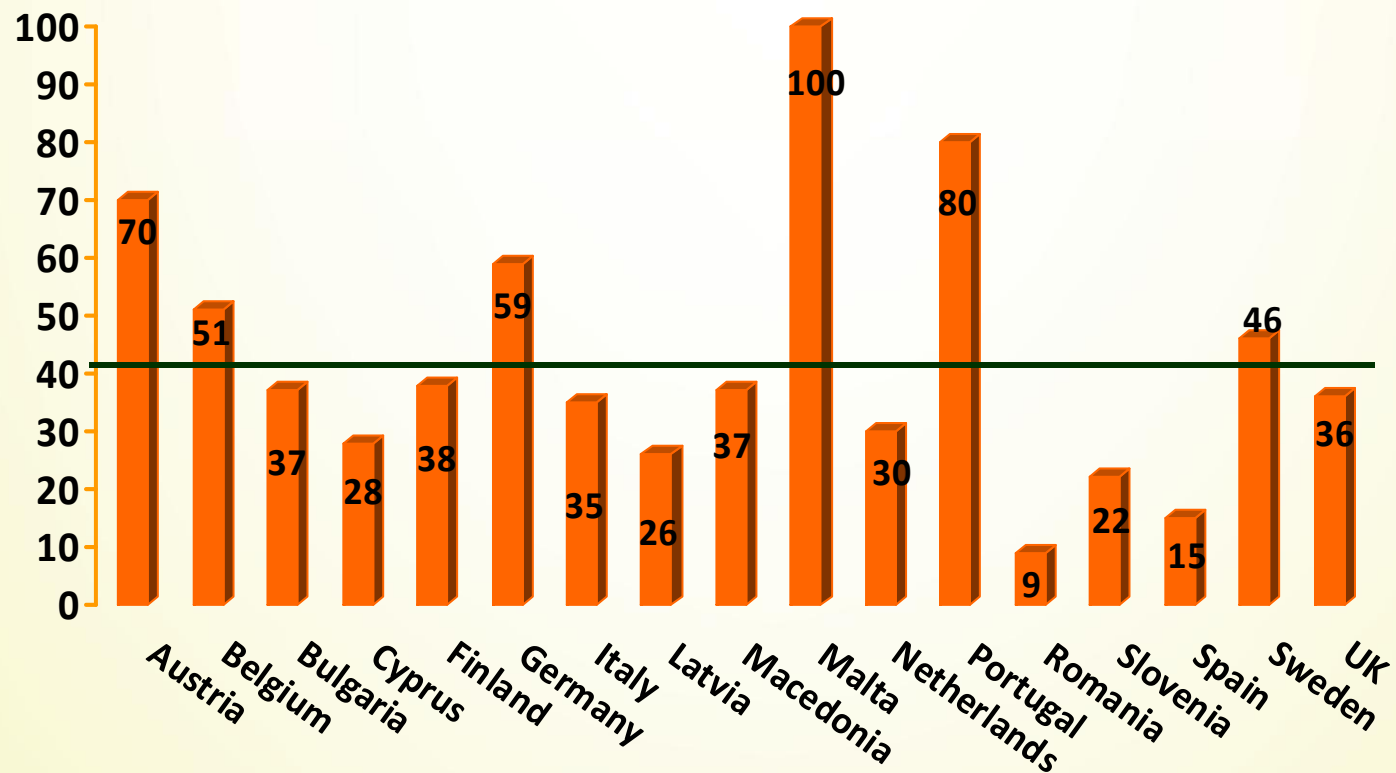
Organization Level - Benchmark
The Patient's right to be believed



**The evaluation related to the patient's right to be believed is sufficient.
The average value, 44 out of 100, is exceeded by 6 countries**

Organization Level - Benchmark

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

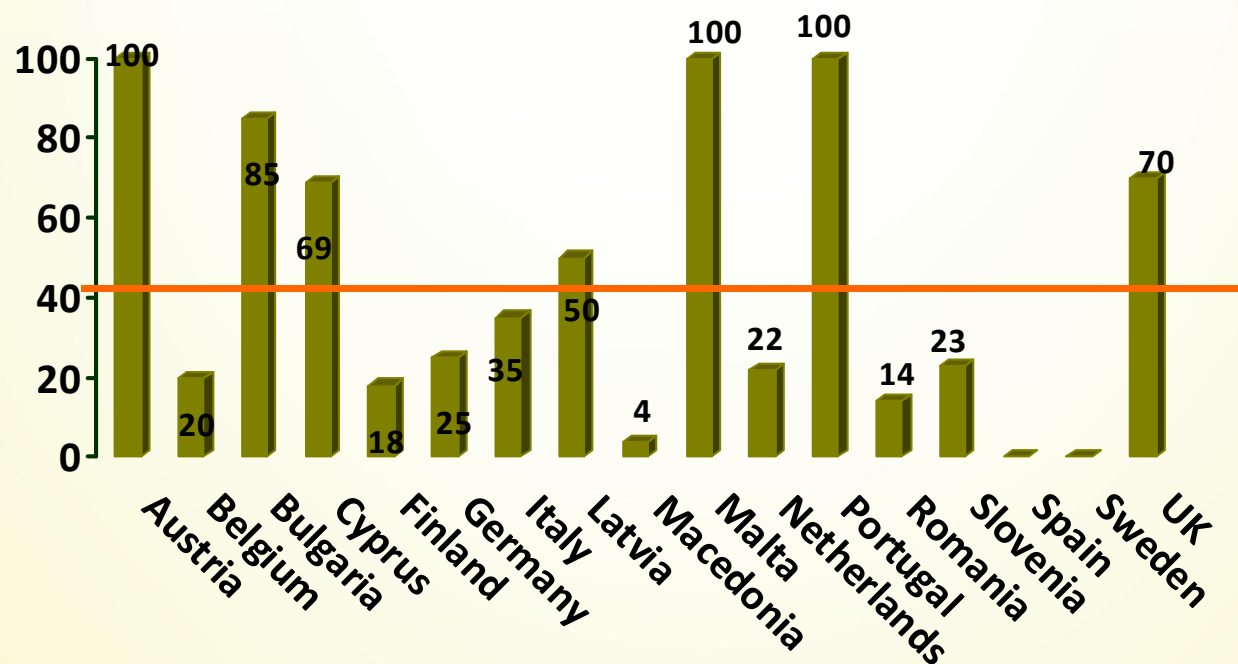


The evaluation related to the patient's right to have pain treated and managed at the earliest possible stage is sufficient.

The average value, 42 out of 100, is exceeded by 6 countries

Organization level - Benchmark

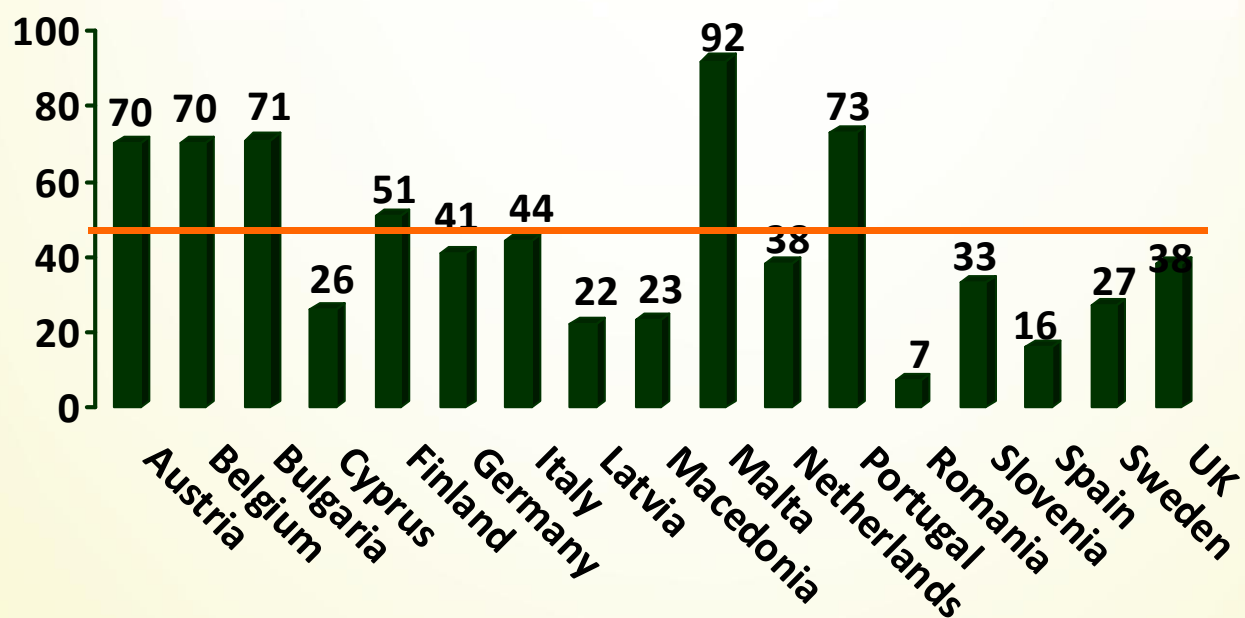
The Patient's right of access to the best possible technologies and therapies for pain treatment and management



The evaluation related to the patient's right of access to the best possible technologies and therapies for pain treatment and management is sufficient. The average value, 43 out of 100, is exceeded by 7 countries

Organization level - Benchmark

The Patient's right to be informed about all the pain management options available

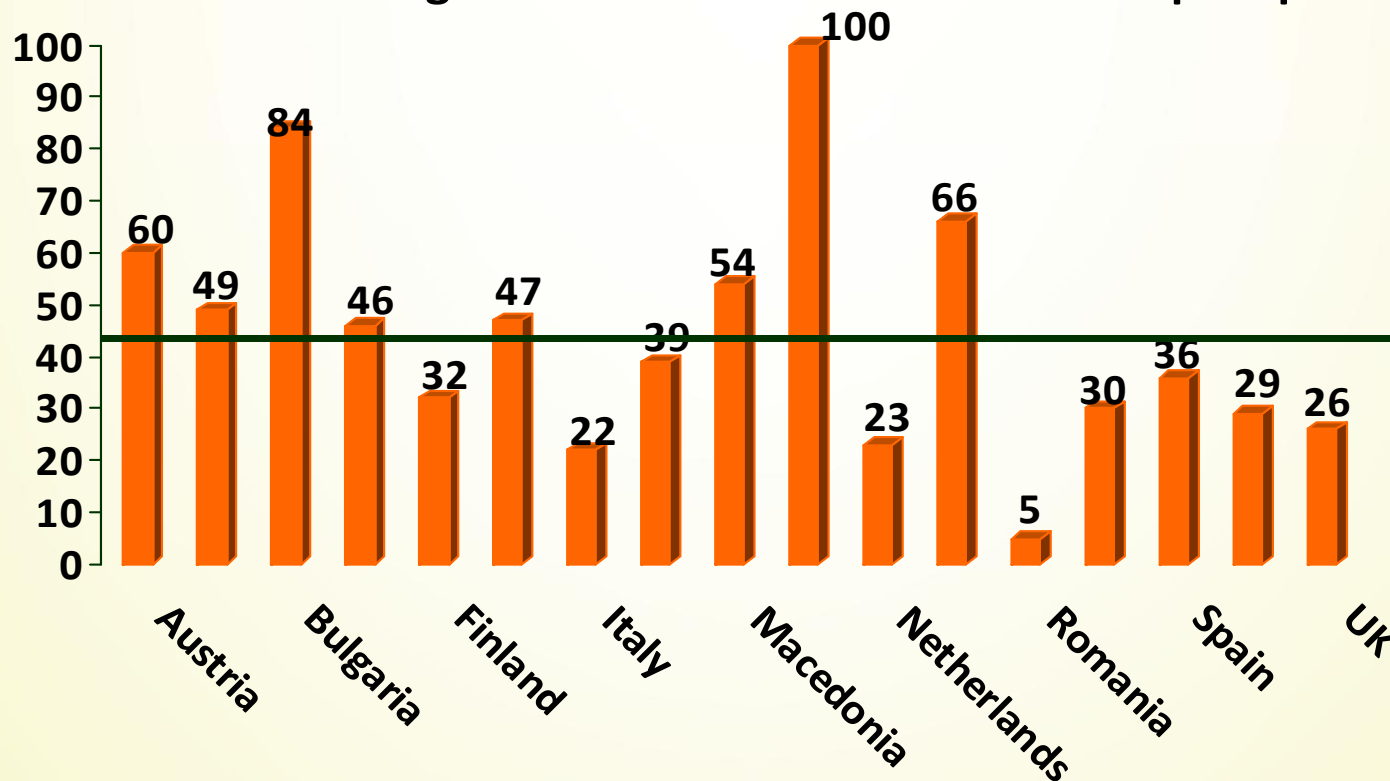


The evaluation related to the patient's right to be informed about all the pain management options available is sufficient.

The average value, 44 out of 100, is exceeded by 6 countries

Organization level - Benchmark

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 8 countries

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

The Right to avoid unnecessary suffering and pain	Right to be believed	Right to have pain treated at the earliest stage	Right of access to the best possible therapies	Right to be informed	Right to live with the least amount of pain possible	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
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

ACCORDING TO THE INFORMATION COLLECTED BY THE MINISTRIES OF HEALTH:

- **At European level**, 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.

- **At national level**, the Right to avoid unnecessary suffering and pain is not respected in 6 Countries, hardly respected in Portugal, almost respected in Italy, fully respected in Sweden.

- 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, Portugal.

- 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, Portugal.

- 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, Portugal.

- 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 and Portugal.
- 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, Sweden.

PROFESSIONALS, IT'S YOUR TURN!

- The work presented in this survey could be integrated and improved upon and therefore all suggestions will be most welcome.
- One of the most important factors is the integration of the collected data with those supplied by the professionals. This would help us to obtain a comprehensive picture of the overall situation.
- Therefore, on the basis of these assumptions, we are committed to prepare a second edition of the present survey to be presented in the second half of 2013.

SUMMARY

- As a whole, the content shows clearly that something is wrong across Europe in the behavior of chronic pain patients but also in the behavior towards them. It shows that patients' associations have done a lot to improve the situation for chronic pain patients and empower them, but there is still a lack of interest from the healthcare society in general and the Institutions in particular in accepting their responsibility and in the willingness to work together with the patients to implement best practices according to the patients view.
- With a positive and constructive approach, the survey emphasizes also the positive aspects and those of excellence in order to improve the culture of the fight against pain in the various European countries.
- This work is a contribution to reflection, hopefully useful to stir interest in those who hold institutional roles and are responsible for policy decisions. Professionals, civil society organizations and the general public are also 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 has achieved over the last few months an increased involvement and appreciation to the point that it is planning a II^o edition later this year which will collect additional data. On the other, it is part of a more ambitious study: it aims at identifying both at national and at European level guidelines and recommendations against pain. To achieve this goal, we welcome everyone's contribution.

21 GOOD PRACTICES FROM A CIVIC POINT OF VIEW

- 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.
- We have also received a list of Good Practices by the Ministries of Health of Belgium, Italy, Malta and Slovenia.

LIFE GOES ON, EVEN WITH PAIN, 7 DAYS A WEEK, 24 HOURS A DAY

- The civic survey 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).

31 CHRONIC PATIENTS' ASSOCIATIONS AND CIVIC ORGANIZATIONS INVOLVED IN THE SURVEY (I)

- Austria: Europäische Arbeitsgemeinschaft Österreich (Eurag-The European Federation of Older People Austria); LKH-Bruck-Mur.
- Belgium: Vlaamse Pijnliga.
- Bulgaria: Index Foundation; 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.
- Cyprus: European social forum cyprus (Esfc).
- Finland: Suomen Kipu ry (Finnish Pain Association).
- Germany: Deutsche Schmerzliga e.V. (German Pain League).
- Italy: Cittadinanzattiva.
- Latvia: Pacientu Ombuds (Patients' Ombud Office); Latvian Diabetes Association.
- Macedonia: Medicine and Ecology Research Centre (Merc); Nora.
- Malta: Malta Health Network; Arthritis and Rheumatism Association Malta.

31 CHRONIC PATIENTS' ASSOCIATIONS AND CIVIC ORGANIZATIONS INVOLVED IN THE SURVEY (II)

- **Nederland:** Stichting Pijn Platform Nederland; Foundation Pain-Hope; Fibromyalgie en Samenleving (Fes).
- **Portugal:** Rede Integrada de Associações de Doença Crónica nos Açores (Riadca); Associação Atlântica de Apoio Doente Machado-Joseph.
- **Romania:** Myeloma Euronet Romania.
- **Slovenia:** Zavod Viva; Fibromyalgia Patient Association.
- **Spain:** Red de Fibromialgia, Síndrome de Fatiga Crónica y Sensibilidad Química Múltiple (Redefmsfcsqm); Asociación Coruñesa de Fibromialgia y Fatiga Crónica (Acofifa).
- **Sweden:** Sveriges Fibromyalgiförbund (Fibromyalgia Association of Sweden).
- **United kingdom:** BackCare; Pelvic Pain Support Network.

AN INVITATION

- Active Citizenship Network (ACN) has the pleasure to invite all of you to the VII European Patients' Rights Day, which will be held tomorrow 16th May 2013 here in Brussels.
- The conference will take place in the European Economic and Social Committee, Room VM3 (2nd floor, Van Maerlant Building, 2 rue Van Maerlant).
- Title: "European Citizens' rights: patients' involvement and Cross Border Care"

Thanks for your attention!

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