

## Joint Declaration of the Platform for the Social Impact of Pain in Portugal Recommendations for Action

English translation of the Portuguese version from March 2019

### Preamble

According to the *International Association for the Study of Pain (IASP)*, pain is "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."<sup>1</sup>

This definition means that: pain is not only a sensory experience but a complex phenomenon involving emotions and other components, and it must be approached according to a biopsychosocial model; pain is a subjective phenomenon, each person feels pain in his or her own way; there are no biological markers to objectively characterize pain; there may be no direct relationship between the cause and pain (especially chronic pain); sometimes there is pain without it being possible to find a physical injury that gives rise to it<sup>2</sup>.

In Europe<sup>3</sup>, there are more than 740 million people<sup>4</sup>, most of whom suffer an episode of intense pain at some point in their life. For approximately 20% of the adult population in Europe, this pain is chronic, from moderate to severe<sup>5</sup>, episodic, persistent or variable<sup>6</sup>. In other words, there are currently 150 million people suffering from pain, a number that roughly corresponds to the population of Germany and France<sup>7</sup>.

In Portugal, the prevalence of chronic pain is estimated at 36.7%<sup>8</sup>.

Chronic pain and associated disability reduce a person's health and quality of life, interfering with daily activities on a personal, family and work/professional level, as well as sleep, exercise and leisure. Chronic pain also has a negative impact on the lives of family members and caregivers and is often undervalued. Early retirement, work absenteeism, job changes and disability pensions are frequent consequences of chronic pain<sup>7, 9, 10, 11</sup>.

With over 500 million days of illness per year in Europe, musculoskeletal pain accounts for almost 50% of all absences from work lasting at least three days and 60% of permanent incapacity to work<sup>11</sup>. Chronic pain is predictably one of the main reasons why people leave the labour market prematurely and it contributes significantly to retirement for reasons of disability<sup>12</sup>.

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<sup>1</sup> <https://www.iasp-pain.org/AboutIASP/>

<sup>2</sup> <http://www.aped-dor.com/index.php/sobre-a-dor/a-dor.html>

<sup>3</sup> Note: data from 37 countries; data not available in Andorra, Armenia, Azerbaijan, Belarus, Georgia, Iceland, Liechtenstein, Luxembourg, Malta, Monaco and Vatican City.

<sup>4</sup> Eccleston, C., Wells, C., & Morlion, B. (2017). *European Pain Management*. Oxford, UK: Oxford University Press, ISBN: 9780198785750 Available at:

<http://oxfordmedicine.com/view/10.1093/med/9780198785750.001.0001/med-9780198785750-chapter-1>

<sup>5</sup> Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *European journal of pain*, 10(4), 287-287. Available at: <https://doi.org/10.1016/j.ejpain.2005.06.009>

<sup>6</sup> Eccleston, C., Wells, C., & Morlion, B. (2017). *European Pain Management*. Oxford, UK: Oxford University Press, ISBN: 9780198785750 Available at:

<http://oxfordmedicine.com/view/10.1093/med/9780198785750.001.0001/med-9780198785750-chapter-2>

<sup>7</sup> <https://www.sip-platform.eu/resources/details/sip-thematic-network-2018-joint-statement>

<sup>8</sup> Azevedo, L. F., Costa-Pereira, A., Mendonça, L., Dias, C. C., & Castro-Lopes, J. M. (2012). Epidemiology of chronic pain: a population-based nationwide study on its prevalence, characteristics and associated disability in Portugal. *The journal of pain*, 13(8), 773-783. Available at: [https://www.jpain.org/article/S1526-5900\(12\)00664-5/fulltext](https://www.jpain.org/article/S1526-5900(12)00664-5/fulltext)

<sup>9</sup> Manjani, D., Paul, D. B., Kunnumpurath, S., Kaye, A. D., & Vadivelu, N. (2014). Availability and utilization of opioids for pain management: global issues. *The Ochsner Journal*, 14(2), 208-215. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4052588/>

<sup>10</sup> Breivik, H. et al (2013) The individual and societal burden of chronic pain in Europe: the case for strategic prioritisation and action to improve knowledge and availability of appropriate care. Available at: <https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-13-1229>

<sup>11</sup> Bevan, S. (2013). Reducing temporary work absence through early intervention: The case of MSDs in the EU. *The Work Foundation*, 2. Available at:

<https://www.bl.uk/collection-items/reducing-temporary-work-absence-through-early-intervention-the-case-of-msds-in-the-eu>

<sup>12</sup> Saastamoinen, P., Laaksonen, M., Kääriä, S. M., Lallukka, T., Leino-Arjas, P., Rahkonen, O., & Lahelma, E. (2012). Pain and disability: a prospective cohort study. *Pain*, 153(3), 526-531. Available at: <https://www.sciencedirect.com/science/article/pii/S0304395911006683>



In 2016, according to the Global Burden of Disease study<sup>13</sup>, worldwide, lower back pain and cervicgia had a prevalence of 750 million people, with 313 million new cases that year, resulting in 86,584 million years of life lived with disability<sup>14</sup>. In Portugal, lower back pain is situated in first place in the ten leading causes of years of life lived with disability, and neck pain is in fourth place, placing it in front of diseases such as asthma, diabetes and cardiovascular disease<sup>15</sup>.

In our country, the direct and indirect costs of health care associated with pain are high, with hospitalisation being the largest component of direct costs and social benefits the largest share of indirect costs. Estimates in Portugal in 2010, taking only lower back pain into account, point to costs in the order of 738.85 million euros, of which 280.95 million euros were due to absenteeism caused by short-term disability and 458.90 million euros were due to the reduction in the volume of employment due to early retirement and other forms of non-participation in the labour market<sup>16</sup>.

It is thus found that chronic pain affects more people and has a more significant impact than diabetes, heart disease or cancer.

## Societal Impact of Pain - SIP

*The "Societal Impact of Pain"*<sup>17</sup> (SIP) has the following objectives:

- To raise awareness of the relevance of the impact of pain on our societies, health systems and economic systems;
- The sharing of information and best practices among all Member States of the European Union;
- Developing and promoting policy strategies and activities at a European level for better pain management in Europe.

The SIP platform supports partners in the development of national platforms that offer advice and information regarding the social impact of pain by improving training and sharing best practices.

## SIP Portugal

The Platform for the Social Impact of Pain in Portuguese Society (SIP Portugal) brings together a heterogeneous and informal group of national representatives of organisations, scientific societies and patient associations concerned with the social impact of pain. Its added value translates into the possibility of dialogue between all the participants, in order to speak with one voice, ensuring greater awareness of the social impact of pain and the promotion of targeted policies.

In Portugal, the objectives of this Platform are now focused on employment and education.

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<sup>13</sup> <http://ghdx.healthdata.org/gbd-2016>

<sup>14</sup> The term "years of life lived with disability" corresponds to QALYs - *Quality-adjusted life years*. For more information on this measure see: <https://doi.org/10.5324/nje.v15i2.217>

<sup>15</sup> GBD 2016 Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet*. 2017; 390(10100): 1211-1259. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5605509/>

<sup>16</sup> Gouveia, M., & Augusto, M. (2011). Indirect costs of chronic pain in Portugal. *Revista Portuguesa de Saúde Pública (Portuguese Public Health Journal)*, 29(2), 100-107. Available at: [http://www.scielo.mec.pt/scielo.php?script=sci\\_arttext&pid=S0870-90252011000200002](http://www.scielo.mec.pt/scielo.php?script=sci_arttext&pid=S0870-90252011000200002)

<sup>17</sup> The Societal Impact of Pain (SIP) is an international platform created in 2009 as a joint initiative of the European Pain Federation (EFIC) and the pharmaceutical company Grünenthal GmbH. Additional information: <https://www.sip-platform.eu/en>



## Joint Declaration of the Platform for the Social Impact of Pain in Portugal

This joint statement presents the common position of all those involved and proposes actions to be taken, relevant to pain, in two categories: **employment and education**.

There is a need to develop policies and design action strategies so that many of the key problems identified are reduced. This is only possible if there is an effective and preventive intervention of public policies in health.

## Recommendations for Action

### 1. Employability

The following measures aim to promote the maintaining of work or professional reintegration of people with chronic pain, in order to reduce absenteeism and presenteeism, as well as early retirement due to disability. The aim is to promote the implementation of integrated and inclusive measures for adaptation, training and the promotion of productive capacity in regard to the work of people with chronic pain, recommending actions of an urgent nature:

#### 1.1. Work schedule:

- a. Adaptability and flexibility, either in full daytime or shift work, at night and/or with irregular shifts that vary between night and day;
- b. Exemption from extraordinary work;
- c. Appropriate pause and/or rest periods.

#### 1.2. Workstation:

- a. Adaptation of the workplace/station;
- b. Promotion of ergonomic conditions and functional adaptation;
- c. Possibility of working from home and/or telecommuting;
- d. Facilitation of professional retraining;
- e. Management of travel in the context of work;
- f. Implementation of strategies to promote movement/exercise of 20 to 30 minutes per day.

#### 1.3. Human Resources:

- a. Training and awareness about the problem of pain in a work context;
- b. Training on Strategies and Techniques for Motivation and Management of employees with chronic pain;
- c. Need for stronger links with health institutions and services;
- d. Vigilance regarding stigma, discrimination and workplace coercion.

#### 1.4. Occupational Medicine:

- a. Suitability to the needs of people with chronic pain, with effective liaisons with the other services (administrative, human resources and health);
- b. Need to comply with social security assessments.

#### 1.5. Support Group:

- a. Possibility of creating a support group for people with chronic pain within a company/employer, without negatively affecting the working hours, the employee or the employer.

## **2. Education**

The following measures are intended to promote training, education and awareness-raising in relation to pain and directed at the public/media; health professionals; education professionals; patients, relatives and caregivers:

### **2.1. Training for the public/media:**

- a. Awareness campaigns/programmes on the social impact of chronic pain in Portugal;
- b. Participation and involvement of health professionals and testimonies of people with chronic pain in the media;
- c. Celebration of commemorative days/thematic dates associated with chronic pain through various communication actions on the theme;
- d. Involvement of different health sector partners in the discussion and debate on chronic pain.

### **2.2. Training for health professionals and students:**

- a. Physiology and treatment of pain;
- b. Interpersonal and communicational skills;
- c. Humanised communication skills in the context of vulnerability;
- d. Emotional intelligence;
- e. Organisation and participation in congresses, meetings and other events;
- f. Promotion of training activities; in pre-graduate curricula, in postgraduate courses, masters/doctorates in pain and other specialised programs of study in chronic pain;
- g. Encouraging the improvement of the university curriculum for education and training in pain, fostering a multidimensional and interdisciplinary approach.

### **2.3. Training aimed at education professionals and the school community:**

- a. Physiology and impact of pain on student achievement;
- b. Importance of curricular adequacy in physical education and/or other disciplines for children suffering from chronic pain and inclusion in the Special Educational Needs program under Decree-Law no. 54/2018 of July 6;
- c. Importance of pedagogical flexibility in the undertaking of assignments and evaluation tests (without prejudice to the student). To evaluate the need for a legal framework and the inclusion of children in the scope of Special Educational Needs;
- d. Pain education - in subjects such as Projects and/or Citizenship and Development, among others - referring to the topic and broaching the subject of pain and its consequences with children;
- e. Interpersonal and communicational skills;
- f. Involve schools in early education regarding issues of chronic pain and prevention;
- g. Involvement of schools and the school community in information, education and training for chronic pain.

### **2.4. Training for patients, families and caregivers**

- a. Holding of conferences, meetings, seminars and other thematic initiatives;
- b. Encouraging the use of early treatment and dissemination of strategies for adherence to therapy/guidelines;
- c. Promotion of healthy lifestyles and prevention of risk factors;
- d. Health literacy and patient empowerment programmes for self-management of the disease;
- e. Campaigns that encourage people with chronic pain to seek help and avoid isolation.



**This Statement is endorsed by:**



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