

## SIP position on the importance of addressing cancer related pain management in the Europe's Beating Cancer Plan and beyond.

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### Key recommendations

SIP calls upon EU and national policymakers to:

- Establish and/or use **pain as a quality indicator** in the assessment of healthcare systems' quality and thus contribute to assessing the societal impact of pain and build on existing initiatives and opportunities to fill the data gap on the societal impact of pain.
- Reference the inclusion of **standards for the management of cancer-related pain** across Europe to improve cancer pain management, promote quality of care and reduce variation and inequalities across Europe.
- Make **resources for cancer care services and treatments** available.
- Encourage Member States to provide an appropriate level of **education and training** in pain assessment and management and other principle of palliative care to all healthcare professionals involved in the care or patients with cancer related pain.
- Promote and allocate adequate **funding** to the development of **pain research**.

### Background

The Europe's Beating Cancer Plan will be published by the European Commission by the end of 2020. The new European cancer plan will set out actions that support, coordinate or supplement Member States' efforts to improve the prevention, detection, treatment and management of cancer in the EU.

In the process of developing the new Cancer Plan, the European Commission is engaging with the research community, healthcare professionals, policymakers, non-government organisations (NGOs,) patients, industry, and Member States (primarily responsible for healthcare) through public and targeted consultations to gather views on the scope and actions of the Cancer Plan.

Within this framework, the Societal Impact of Pain (SIP) Platform [responded](#) to the two public consultations<sup>1</sup> on the Roadmap for the Cancer Plan on the identification of priority areas, and the scope for future action. Through this position paper SIP would like to further highlight the importance of **addressing pain management** from a multi-professional perspective to improve quality of life for patients and survivors as well as **palliative care** and **overall treatments**.

### The burden of cancer related pain

#### I. What is pain?

Pain is an "unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage".<sup>2</sup> Acute pain is pain of recent onset and limited duration due to injuries, illness, or as a result of surgical interventions, e.g. post-operative pain, acute headaches, strain trauma and burns, fractures, activated arthrosis, and dental pain<sup>3</sup>. However, acute pain which persists for longer than three months, is generally classified as chronic pain.<sup>4</sup> This process is known as 'chronification'. "Biologic factors involved in this transition include central sensitization, neuroplastic changes, altered pain modulation, and changes to the "neuromatrix". Chronic pain may involve irreversible pathophysiologic changes, so interrupting the cascade of events that allows acute pain to advance to chronic pain is of crucial importance."<sup>5</sup> The chronification can also be the result of the inadequacy of pain management (i.e., suboptimal pain management) in all clinical settings.

Many patients experience post-operative suboptimal pain management and endure pain that could be decreased if enough knowledge of pain management would exist in the post-surgery wards.<sup>6</sup>

<sup>1</sup> European Commission. Available at <https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12154-Europe-s-Beating-Cancer-Plan>. Accessed September 2020.

<sup>2</sup> Raja, Srinivasa N., Carr, Daniel B.b; Cohen, Milton et al. 2020. The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. PAIN:161(9):1943-1944.

<sup>3</sup> CHANGE PAIN®. Available at [http://www.change-pain.com/grt-change-pain-portal/change\\_pain\\_home/acute\\_pain/pain\\_basics/definition\\_of\\_pain/pain\\_is.../en\\_EN/318500008.jsp](http://www.change-pain.com/grt-change-pain-portal/change_pain_home/acute_pain/pain_basics/definition_of_pain/pain_is.../en_EN/318500008.jsp). Accessed September 2020.

<sup>4</sup> MedlinePlus. Available at <https://medlineplus.gov/magazine/issues/spring11/articles/spring11pg5-6.html>. Accessed September 2020.

<sup>5</sup> Joseph V.Pergolizzi Jr.MD et al. 2014. Treating Acute Pain in Light of the Chronification of Pain. Pain Management Nursing: 15(1):380-390.

<sup>6</sup> Schafheutle EI, Cantrill J Cantrill JA, Noyce PR 2000. Why is pain management suboptimal on surgical wards? Journal of Advanced Nursing: 33(6), 728-737.

Pain can also arise due to other illnesses (known as “co-morbidity”) and can require palliative care. Further, pain is commonly connected with numerous chronic health conditions, such as cancer and musculoskeletal diseases.<sup>7 8 9 10</sup> Indeed, chronic pain is one of the most common co-morbidities of other long-term illnesses.<sup>11</sup>

## II. Cancer related pain

Pain is the most common symptom of cancer at diagnosis<sup>12</sup> and rises in prevalence throughout and beyond cancer treatment.<sup>13</sup> Most cancer pain is caused by a tumour pressing on bones, nerves or other organs in the body and it can also be related to cancer treatment.

Cancer related pain can be acute or chronic. Persistent cancer pain can, in some individuals, lead to the development of chronic widespread pain induced by plastic changes in the sensory nervous system.<sup>14</sup>

**Cancer survivors** continue to live with physical and psychological symptoms associated with pain (such as cardiopulmonary compromise, fatigue, pain, neuropathies, reduced physical function, depression, and anxiety)<sup>15</sup> that interferes with functioning and negatively affects quality of life:

- 66% will survive for at least 5 years and 40% will be alive more than 10 years after diagnosis.<sup>16 17</sup>
- Between 33% and 40% of cancer survivors suffer from chronic pain, often neuropathic in nature.<sup>18 19</sup>

For patients who live with **progressive advanced disease** (incurable disease), pain is a very common symptom:

- 1.9 million European cancer patients die from their disease each year.<sup>20</sup>
- 66% will experience pain before death and 55% will experience moderate-to-severe intensity pain.<sup>21 22</sup>

## The challenges

### I. Suboptimal pain management

The consequences of suboptimal pain management on quality of life, physical functioning, and psychological distress can be devastating. Between 33% and 40% of cancer survivors suffer from chronic pain and further studies have shown that at least one-third of patients are often undertreated due to inadequate attention to pain during regular oncological treatment. Adequate treatment of pain in acutely managed cancer patients, and in those with life prolonging therapies, can reduce the need for sickness absence and disability. Adequate treatment of pain can provide better quality of life to all cancer patients, regardless of their age, gender or employment status.

Pain treatment is also highly relevant to palliative care. Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief but also spiritual and psychosocial support from diagnosis to the end of life and bereavement.<sup>23</sup>

<sup>7</sup> Roberto A et al. 2016. Prevalence of neuropathic pain in cancer patients: Pooled estimates from a systematic review of published literature and results from a survey conducted in 50 Italian palliative care centers. *Journal of Pain and Symptom Management*: 51(6):1091-1102.

<sup>8</sup> New Practical Approaches to Chemotherapy-Induced Neuropathic Pain: Prevention, Assessment, and Treatment. Majithia, N, Loprinzi, CL and Smith, TJ. pii: 219814, 15 Nov 2016, *Oncology (Williston Park)*, Vol. 30(11).

<sup>9</sup> IASP. Recommendations for pain treatment services. Available at <http://issuu.com/iasp/docs/n12-mechanisms>. Accessed September 2020.

<sup>10</sup> Mieritz RM, Thorhauge K, Forman A, et al. 2016. Musculoskeletal Dysfunctions in Patients With Chronic Pelvic Pain: A Preliminary Descriptive Survey. *JMPT*: 39(9):616-622.

<sup>11</sup> Barnett, K, et al. 2012. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet*:380(9836):37-43.

<sup>12</sup> World Health Organisation. Data and statistics. Available at <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/data-and-statistics>. Accessed September 2020.

<sup>13</sup> Breivik H, Cherny N, Collett B, deConno F, Filbet M, Foubert AJ et al. 2009. Cancer-related pain: A pan-European survey of prevalence, treatment, and patient attitudes. *Ann Oncol*: 20(8):1420-33.

<sup>14</sup> Kosek et al. Do we need a third mechanistic descriptor for chronic pain states? *PAIN* 2016; 157(7):1382-6.

<sup>15</sup> Bruehl S, Burns JW, Chung OY, Chont M. Pain-related effects of trait anger expression: neural substrates and the role of endogenous opioid mechanisms. *Neurosci Biobehav Rev*. 2009; 33(3):475-91.

<sup>16</sup> Ferlay J, Steliarova-Foucher E, Lortet-Tieulent J, Rosso S, Coebergh JW, Comber H et al. Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. *Eur J Cancer* 2013; 49(6):1374–403.

<sup>17</sup> Glare PA, Davies PS, Finlay E, Gulati A, Lemanne D, Moryl N et al. Pain in cancer survivors. *J Clin Oncol* 2014; 32(16):1739–1747.

<sup>18</sup> Paice JA. Chronic treatment-related pain in cancer survivors. *Pain* 2011; 152(Suppl.):S84–S89.

<sup>19</sup> Seretny M, Currie GL, Sena ES, Ramnarine S, Grant R, MacLeod MR et al. Incidence, prevalence, and predictors of chemotherapy-induced peripheral neuropathy: A systematic review and meta-analysis. *Pain* 2014; 155(12):2461–2470.

<sup>20</sup> World Health Organisation. Data and statistics. Available at <https://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/data-and-statistics>. Accessed September 2020.

<sup>21</sup> van den Beuken-van Everdingen MH, Hochstenbach LM, Joosten EA, Tjan-Heijnen VC, Janssen DJ. Update on prevalence of pain in patients with cancer: Systematic review and metaanalysis. *J Pain Symptom Manage* 2016; 51:1070–90.

<sup>22</sup> Ferlay J, Steliarova-Foucher E, Lortet-Tieulent J, Rosso S, Coebergh JW, Comber H et al. Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. *Eur J Cancer* 2013; 49(6):1374–403.

<sup>23</sup> World Health Organization. Definition of palliative care. Available at <https://www.who.int/news-room/fact-sheets/detail/palliative-care>. Accessed September 2020.

## **II. Multi-professional approach**

Often cancer survivors or patients undergoing cancer treatment need support from other professions to manage their pain both physically and emotionally (e.g., a psychologist, a physiotherapist, a nutritionist). Good quality of life for cancer patients is the result of a multi-professional approach and not the responsibility of one single discipline. In addition, chronic pain, such as that resulting from post-surgery or tissue damage due to treatment, is often forgotten when accounting for a better quality of life for survivors.

## **III. Inequalities**

Significant inequalities in access to cancer treatments and novel medicine are evident across Europe, while variances in the performance of health systems add to the burden on patients<sup>24</sup>, particularly due to the migration of medical doctors from Eastern European countries to other EU member states.

## **Our asks and commitments**

### **Pain as a quality indicator**

We ask the European Commission to explore opportunities to build on existing instruments which are available to define, establish and/or use pain as an indicator in the assessment of healthcare systems' quality. This will contribute to assessing the societal impact of pain and build on existing initiatives and opportunities to fill data gaps on the societal impact of pain.

#### *Our commitments:*

- Healthcare professionals, patient groups, and researchers working on pain contribute to the implementation of the WHO's 11th revision of the International Classification of Diseases (ICD-11) that includes chronic pain as a separate entry.
- Healthcare professionals and patients provide their expertise and perspective in the creation of patient- relevant indicators.

### **Standards for the management of cancer-related pain care**

We ask the European Commission to reference the inclusion of standards for the management of cancer-related pain across Europe to improve multi-professional cancer pain management, promote quality of care, and reduce variation and inequalities across Europe.

#### *Our commitments:*

- Healthcare professionals and patients provide their expertise and perspective in the creation of standards for the management of pain care.

### **Resources for cancer care services and treatments**

We ask the European Commission:

- To promote needs assessment methodologies across member states to meet present and future needs of cancer patients, through relevant frameworks.
- To put in place a strategy on workforce planning to ensure the sustainability of cancer care services and cancer pain treatment across EU.
- To encourage Member States to include pain assessment and management in all cancer services and all patient pathways as part of standard reimbursed services.

#### *Our commitments:*

- Healthcare professionals and patients provide their expertise and perspective to contribute to assess needs and strategies.

### **Formal and continuous education**

We ask the European Commission to encourage Member States to provide an appropriate level of education and training in pain assessment and management, and other principles of palliative care to all healthcare professionals involved in the care or patients with cancer related pain.

<sup>24</sup> Organisation for Economic Co-Operation and Development. Cancer Care: Assuring quality to improve survival, 2013. Available at <https://www.oecd.org/health/cancer-care-9789264181052-en.htm>. Accessed September 2020.

#### Our commitments:

- Civil society, healthcare professionals and patient groups share best practices on pain education for patients, healthcare professionals, politicians, and the broader community.
- Civil society, healthcare professionals, and patient groups continue working on their educational programs and projects targeted to these audiences.

#### Pain research

We ask the European Commission:

- To allocate adequate funding to the development of research into pain and other causes of distress, in cancer and palliative care patients, and invite Member States to do the same in their national research plans.
- To promote multi-professional pain research using routinely collected data on pain, the newly adopted ICD-11 classification, updated national cancer registries, and digital health solutions involving the patient perspective.

#### Our commitments:

- Industry representatives, research institutions, healthcare professionals and patient groups build on the achievements of public private research partnerships such as Innovative Medicines Initiative (IMI) with the aim of translating them into real world applications.
- Patient groups and healthcare professionals foster the dissemination of research outcomes to their community and support a patient-led approach to research.

*SIP remains available for further discussions with the European Commission, the Members of the European Parliament and the Council for future cooperation to ensure our recommendations are implemented by both the EU, and national institutions to help both cancer survivors and patients with progressive advanced disease who live with pain.*

#### Sources

- SIP 2016 Policy recommendations – The relevance of pain in cancer care and rehabilitation - <https://www.sip-platform.eu/resources/details/sip-2016-wg3-recommendations-on-the-relevance-of-pain-in-cancer-care-and-rehabilitation>.
- SIP Thematic Network 2018 - Joint Statement - <https://www.sip-platform.eu/resources/details/sip-thematic-network-2018-joint-statement-now-available-in-several-languages>
- Background briefing. The 11th revision of the WHO International Classification of Diseases (ICD-11) - [https://www.sip-platform.eu/resources/tag/icd-11?file=files/editor/events/EFIC/2019/ICD-11%20Infographic\\_FINAL\\_DIGITAL.pdf](https://www.sip-platform.eu/resources/tag/icd-11?file=files/editor/events/EFIC/2019/ICD-11%20Infographic_FINAL_DIGITAL.pdf)

#### About SIP

The 'Societal Impact of Pain' (SIP) platform is a multi-stakeholder partnership led by the [European Pain Federation EFIC](#) and [Pain Alliance Europe \(PAE\)](#), which aims to **raise awareness of pain** and **change pain policies**.

The platform provides opportunities for discussion for health care professionals, pain advocacy groups, politicians, healthcare insurance providers, representatives of health authorities, regulators, and budget holders.

The scientific framework of the SIP platform is under the responsibility of EFIC and the strategic direction of the project is defined by both partners. The pharmaceutical company [Grünenthal GmbH](#) is the main sponsor of the Societal Impact of Pain (SIP) platform.

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