



Working Group 3 - The relevance of pain in cancer care and rehabilitation

SIP 2016 policy recommendations

Context

The European Union plays a complimentary role with national governments in the fight against non-communicable diseases such as cancer.

In 2009, the European Partnership for Action Against Cancer (EPAAC)ⁱ was set up as a means to coordinate activities across the EU and to advise member states on good practices. This initiative resulted in the first Joint Action EPAAC (JA EPAAC), which had a broad scope and spanned from health promotion to palliative care.

Since 2014, EU member states have come together via the Joint Action on Cancer Control (JA CanCon)ⁱⁱ, to develop the *European Guide on Quality Improvement in Comprehensive Cancer Control* - a compilation of best practices and guidelines to optimise the best cancer patient care and support. Within the framework of JA CanCon there is a work package on recommendations for high-quality survivorship care and comprehensive rehabilitation.

In 2014, the European Commission also established the Expert Group on Cancer Controlⁱⁱⁱ, to provide advice and expertise to the European Commission in formulating and implementing the Union's activities in the field of cancer and foster exchanges of relevant experience, policies and practices between the member states and the various parties involved. It is also the forum for verifying and assessing the outputs and recommendations from JA CanCon.

Estimated pain prevalence in patients with cancer is around 70%. Among patients with advanced cancer, pain prevalence reaches 80%^{iv}.

Most cancer pain is caused by a tumour pressing on bones, nerves or other organs in the body. But also, pain can be related to cancer treatment. For example, chemotherapy can cause numbness and tingling in hands and feet or a burning sensation at the place of injection. Cancer related pain can be acute or chronic.

Pain due to advanced cancer is often not satisfactorily controlled; the estimated amount of under-treatment of cancer pain reaches 30%.

Cancer pain does not end after treatment. In the longer term, approximately 5 to 10% of survivors have chronic severe pain that interferes with functioning.^v Although more comprehensive information about the prevalence of persistent pain in the cancer survivor population is currently lacking, it is known to depend on the type of cancer, co-morbid conditions, and the initial pain management.

Cancer survivors continue to live with physical and psychological symptoms associated with pain (such cardiopulmonary compromise, fatigue, pain, neuropathies, depression and anxiety).^{vi}

The scientific framework of the "[Societal Impact of Pain](#)" (SIP) platform is under the responsibility of the [European Pain Federation EFiC](#)[®]. Cooperation partners for SIP 2016 are [Pain Alliance Europe \(PAE\)](#) and [Active Citizenship Network \(ACN\)](#). The pharmaceutical company [Grünenthal GmbH](#) is responsible for funding and non-financial support (e.g. logistical support). The scientific aims of the SIP symposia have been endorsed by a large number of international and national pain advocacy groups, scientific organisations and authorities.



The consequences of suboptimal pain management on quality of life, physical functioning, and psychological distress can be devastating. 40% of patients report that pain interferes with their activities of daily living^{vii}, and 40% believe that their care providers do not prioritise treating pain over their illness which makes them believe that physicians do not prioritise their quality of life.

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 and 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.^{viii}

Significant inequalities in access to cancer treatments are apparent across Europe, while variances in the performance of health systems add to the burden on patients.^{ix}

The mobility of healthcare professionals across the European Union, whilst representing a fundamental right of EU citizens under the EU treaties, is creating new challenges for the sustainability of cancer care services in some EU member states.

Policy recommendations

- ***Ongoing education and training at all levels***

National governments have a duty to ensure that:

- All involved in the care of patients with cancer have an appropriate level of education and training in pain assessment and management, and other principles of palliative care.
- All those providing clinical services to patients recognise and support the important role of family and informal carers.
- Patients with cancer are empowered and supported to discuss all aspects of their pain, its assessment and management.
- The voice of the patient, including through patient associations, is recognised as an important source of information in service policy development.
- Awareness programmes are instigated for all school teachers to understand the impact on children of witnessing a loved one in pain and of being bereaved, and to support these children.

- ***Research across Europe***

- All research funding bodies have a duty to develop research into pain and other causes of distress, in cancer and palliative care patients.
- Data on pain in patients with cancer, as proposed in ICD-11, should be routinely collected by all providers of cancer care to inform future healthcare policies.
- All member states must support up-to-date accurate cancer registries.
- IT solutions for pain assessment and management should be piloted across populations in Europe.

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- ***The just allocation of resources***

The European Commission must:

- Promote needs assessment methodologies across member states to meet present and future needs of cancer patients at all times, through the Joint Action on Cancer Control and other frameworks.
- Follow up on its work on effective, accessible and resilient health system, and put in a place a strategy on workforce planning to ensure the sustainability of cancer care services and cancer pain treatment across the EU.

National Governments must ensure that:

- Pain assessment and management are an integral part of all cancer services and all patient pathways as part of standard reimbursed services. This must be stated clearly in national cancer strategies and funded.
- All cancer treatment options and relevant guidelines include access to pain assessment and management and the outcomes monitored.
- Patients have access to medication for pain relief at all times.

ⁱ European Partnership for Action Against Cancer (EPAAC): www.epaac.eu/

ⁱⁱ Joint Action on Cancer Control: <http://www.cancercontrol.eu/>

ⁱⁱⁱ European Commission expert group on Cancer Control:

<http://ec.europa.eu/transparency/regexpert/index.cfm?do=groupDetail.groupDetail&groupID=3203>

^{iv} Breivik H, Cherny N, Collett B, de Conno F, Filbet M, Foubert AJ, Cohen R, Dow L. Cancer-related pain: a pan-European survey of prevalence, treatment, and patient attitudes. *Ann Oncol.* 2009 Aug;20(8):1420-33. doi: 10.1093/annonc/mdp001. Epub 2009 Feb

^v Paul A. Glare, Pamela S. Davies, Esmé Finlay, Amitabh Gulati, Dawn Lemannel, Natalie Moryl, Kevin C. Oeffinger, Judith A. Paice, Michael D. Stubblefield and Karen L. Syrjala. Pain in Cancer Survivors. *JCO* May 5, 2014. doi: 10.1200/JCO.2013.52.4629.

^{vi} 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. doi:10.1016/j.neubiorev.2008.12.003. PMID 19146872.

^{vii} Breivik H, Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment, *European Journal of Pain* 2006; 10 (4): 287-333

^{viii} World Health Organization. National cancer control programmes, 2002.

^{ix} Organisation for Economic Co-Operation and Development: Cancer Care: Assuring quality to improve survival, 2013