

A Catalyst for Change: *The European Cancer Patient's Bill of Rights*

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Article 1 European Cancer Patient's Bill of Rights

Article 1: The right of every European citizen to receive the most accurate information and to be proactively involved in his/her care.

European citizens should have:

1.1 Evidence-based public health interventions which can prevent cancer.

1.2 High quality screening and diagnostic services which must be accredited and harmonized to ensure an optimal standard.

1.3 The right to access all information regarding their state of health, and to proactively participate in decision-making regarding their treatment.

1.4 Patient-focused information strategies that clearly state in a form and language that they can understand, their right to an optimal standard of care at all stages of their cancer journey.

1.5 Information that their cancer unit or center satisfies agreed optimal quality thresholds in relation to an appropriate degree of specialization of cancer care.

1.5a Transparency in access to all national anonymized data on treatments and clinical outcomes from health care institutions, cancer registries and independent audit programs, prior to the start of their treatment.

1.6 A clear and transparent personalized care plan for their disease prior to the start of any treatment, with the right to a second opinion.

1.7 Their privacy respected, with the level of confidentiality of their own data to be decided by the patient.

1.8 Information on the research and innovation activities relevant to their cancer that are available locally, nationally and across Europe.

1.9 Information on cancer survivorship and support services for post treatment issues.

1.10 Representation and support through patients' advocacy organizations that empower patients to be an equal partner in all areas that affect their health and wellbeing.

Article 2 European Cancer Patient's Bill of Rights

Article 2: The right of every European citizen to optimal and timely access to appropriate specialised care, underpinned by research and innovation.

European Patients should have:

2.1 Timely access to validated diagnostics, to ensure accurate and earliest possible diagnosis of their cancer.

2.1a Their diagnosis provided to them in an accurate and compassionate manner, by a specialist/experienced clinician

2.2 Timely access to an optimal quality of appropriately specialized care, including relevant clinical research and innovation, to ensure best possible outcomes.

2.3 Care delivered locally wherever possible and centralized where recommended by nationally or internationally approved guidelines and expert treatment recommendations.

2.4 Access to appropriate psychological support at all stages of their cancer journey, to deal with the impact of screening, diagnosis, treatment, quality of life and survivorship.

2.5 The right to choice of location for diagnosis and treatment, even across national borders.

2.6 Rapid access to the latest innovations in diagnosis and treatment for the individual cancer patient following relevant regulatory approval.

2.7 The right to access care based on their need and not on their ability to pay for it.

2.8 The right to expect research to be conducted on their particular cancer type and to be offered access to clinical studies where available and relevant to their condition.

2.9 In the case of children with cancer, the right to be treated in a specialized pediatric oncology center/unit.

Article 3 European Cancer Patient's Bill of Rights

Article 3: The right of every European citizen to receive care in health systems that ensure improved outcomes, patient rehabilitation, best quality of life and affordable health care.

Patients should receive care in health systems that:

- 3.1 Are underpinned by National Cancer Control Programs (NCCPs), organized according to national guidelines and regularly reviewed by external experts, including patient representatives.**
- 3.2 As part of the NCCP, results should be audited to ensure optimal progress and benefit for the cancer patient.**
- 3.3 Provide cost effective care at all stages of the cancer journey, from early diagnosis through treatment and supportive care, that conforms to quality standards of care.**
- 3.4 Address the key issues of long term follow-up and patient survivorship to ensure best quality-of-life and personal fulfillment with active re-integration and participation in society and the work place.**
- 3.5 Ensure optimal pain and symptom management strategies are in place for cancer patients.**
- 3.6 Encourage and maintain sufficient expertise and experience in treating particular cancers, including education and training for all healthcare and allied professionals involved in patient care.**
- 3.7 Recognize patient advocacy organizations as equal partners in all aspects of cancer care, research and innovation.**
- 3.8 Are coordinated by appropriately specialized Multi-disciplinary Teams (MDTs), which must conform to national requirements, driven by recognized pan-European guidelines.**
- 3.9 Have timely and transparent referral and follow-up between community health care/primary care professionals and cancer units or centers.**
- 3.10 Respect the patient, ensuring necessary treatment within an optimal and predetermined period of time.**
- 3.11 Ensure that the patient is protected from harm caused by potentially poor functioning health services, medical malpractice or errors.**

3.12 Recognize and promote high quality clinical research innovation and participation in clinical trials.

3.13 Involve patients, care-givers and patient advocacy organizations in all aspects of design and conduct of patient-centered clinical research.

3.14 Implement and maintain a high-quality integrated palliative care strategy.

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The authors dedicate the *European Cancer Patient's Bill of Rights* initiative to Prof. Donal Hollywood who sadly passed away due to cancer in 2013.

Current List of ECC Partners¹

Cancer Research UK (CRUK)
Centro Nacional de Investigaciones Oncológicas (CNIO), Madrid, Spain.
Chronic Myeloid Leukaemia Advocates Network
Dutch Breast Cancer Organisation (BVN)
Erasmus University Medical Center, Rotterdam, The Netherlands
Europa Donna
EuropaColon
European Alliance for Personalised Medicine (EAPM)
European Cancer Leagues (ECL)
European Cancer Patient Coalition (ECPC)
European Men's Health Forum (EMHF)
European Organisation for the Research and Treatment of Cancer (EORTC)
European Patient's Academy of Therapeutic Innovation (EUPATI)
Hôpital Saint-Antoine, Paris, France.
Inspire 2 Live (I2L)
Istituto Oncologico Veneto, Padova, Italy
Istituto di Ricerche Farmacologiche "Mario Negri" Milan, Italy
International Brain Tumour Alliance (IBTA)
International Confederation of Childhood Cancer Parent Organisations (ICCCPO)
Irish Cancer Society (ICS)
Italian Association of Cancer Patients (AIMaC)
Italian Federation of Volunteer-based Cancer Organizations (F.A.V.O.)
Kings Health Partners Integrated Cancer Centre, London UK
Leiden University Medical Center, Leiden, The Netherlands.(LUMC)
Leukaemia Patient Advocates Foundation (LPAF)
Medical University of Gdansk, Gdansk, Poland.
Medical University Vienna Austria
Myeloma Patients Europe (MPE)
National Cancer Institute, Milan, Italy
Northern Ireland Cancer Research Consumers Forum (NICRCF)
Queens University Belfast, UK (QUB)
Sarcoma UK
Sarcoma Patients EuroNet
Society for Translational Oncology, North Carolina, USA (STO)
University of Cologne, Germany
University of Edinburgh, Scotland
University of Southampton, UK
Vall D'Hebron Institute of Oncology, Barcelona, Spain
VU University Medical Center , Amsterdam, The Netherlands (VUmc)

¹ ECC is actively engaging with other organizations/patient advocacy organizations/non governmental organizations to join the partnership